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ALZHEIMER'S OR DEMENTIA SPECIFIC CARE UNITS:

Should They Be Regulated?

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The paper on regulating the care and treatment of persons with Alzheimer's disease and related disorders in the state of South Carolina was my chief project as an intern with the Joint Legislative Committee on Aging, South Carolina General Assembly, from January to April in 1995. The internship with the Committee was my final step to earning my Master of Science in Gerontology from Baylor University in Waco, Texas.

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The opinions communicated in the paper are not a reflection of those of the Joint Legislative Committee on Aging.

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PRELIMINARY INFORMATION

Background:

Most people have been acquainted with dementia in some way or another. Alzheimer's disease and other related disorders have become a personal issue due to loved ones, friends, or a friend of a friend who has been diagnosed with the disease. However, Alzheimer's and other dementias are still not well understood by not only the average individual, but also by professionals in the field of aging. Progress has been made in the discovery of how best to care for persons with dementia, but not in the cure or prevention of it.

The statistics on the prevalence of Alzheimer's lend evidence to the assumption that special services must be made available to persons with Alzheimer's disease and related disorders (ADRD) and their families and friends. In addition to services, training for the care providers should be molded to the needs of the ADRD patients or clients. Persons with this illness exhibit many symptoms and behaviors that require special attention and care due to their unusual presentation. As the following figures will show, South Carolina will have to be innovative in its response to the increasing prevalence of ADRD among its citizens in the coming years in order to meet the needs of these people who fall prey to the disease.

- Approximately 10%, over 50,000, of those persons aged 65 or older have ADRD
- Over 50% of persons in nursing homes have ADRD
- 38% of those persons aged 85 years or older have ADRD
- According to the 1990 Census, there are 30,749 persons 85+ years in SC
-projected to increase to 66,780 by the year 2000
- Persons 85+ years is the fastest growing population nationally and in SC
-this age group increased 247% from 1980 to 1990
- Persons 85+ years is the group at greatest risk for ADRD

Reference: *Gray Plague of the Twenty-First Century: Meeting the Needs of
Individuals with Alzheimer's Disease, Their Families and Caregivers* (1993)

Obviously, much research and consideration must be given to the state's care for its individuals with Alzheimer's disease and other related disorders.

Joint Resolution Alzheimer's Care Units:

A study on the planning, coordinating, and delivery services for persons with Alzheimer's disease, their families, and caregivers was conducted by the Blue Ribbon Task Force in 1993. The Task Force was created by Act 195 of the General Assembly of South Carolina which directed the Joint Legislative Committee on Aging to complete this study. Many recommendations followed the study after much research and critical evaluation. The Task Force identified ways to improve the service delivery system for persons with ADRD. "Gray Plague of The Twenty-First Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families, and Caregivers" (November, 1993) is the report that came out of the study with all of the Task Force's recommendations.

The recommendations from the Task Force were discussed at the Joint Legislative Committee on Aging's public hearing September 21, 1994. Ruth Seigler, Executive Director of the Division on Aging, Office of the Governor, asked the Committee on Aging to consider the recommendations of the Blue Ribbon Task Force on Alzheimer's Disease and Related Disorders. Following the hearing, the Committee drafted legislation based upon the testimonies given at the hearing about the various aging needs in South Carolina. One particular recommendation from the Task Force that was developed into a bill was the proposal for the Department of Health and Environmental Control, by Joint Resolution, to study whether or not there is a need for special licensing criteria for health care facilities which provide special care units and other programs for Alzheimer's disease and related disorders patients and to report its findings to the Joint Legislative Committee on Aging. The bill was introduced in the House (H. 3212) and in the Senate (S. 329) January 10, 1995.

After some Committee amendments to the bill, the Joint Resolution was ratified (R23) on March 30, 1995 and signed by the Governor April 4, 1995. "*Health care*" was deleted before "*facilities*", and "*special*" was deleted before "*care units*." The Joint Resolution now reads: "The Department of Health and Environmental Control shall study whether there is a need for specific licensing criteria for facilities which provide care units for Alzheimer's patients and other specialized programs for individuals with Alzheimer's and other related

disorders." The bill also directs DHEC to consult with Alzheimer's Disease and Related Disorders Resource Coordination Center, Division on Aging, Office of the Governor and representatives of homes for the aging and nursing home industry (Appendix A).

A study of the perceptions of special care units and the necessary measures for good care for persons with Alzheimer's disease and related disorders has been done by the National Alzheimer's Association (1994). The findings, conclusions, and recommendations merit evaluation by researchers of dementia care and treatment.

ALZHEIMER ASSOCIATION SPECIAL CARE UNITS SURVEY

"ALZHEIMER SPECIAL CARE IN NURSING HOMES: IS IT REALLY SPECIAL?"

There are various definitions of *Special Care Units*. A common definition of a SCU is it is a designated section of a long term care facility for persons with dementia. The National Alzheimer's Association has defined SCUs much more broadly in the survey publication:

"Alzheimer's Special Care Unit/Program means any nursing facility, residential care/assisted living facility, adult congregate living facility, home health agency, adult day care center, hospice, or adult foster home that locks, secures, segregates or provides a special program or special unit for residents with a diagnosis of probable Alzheimer's disease or a related disorder, to prevent or limit access by a resident outside the designated or separated area; and that advertises, markets or otherwise promotes the facility as providing specialized Alzheimer/dementia care services."

The National Alzheimer's Association did a survey of families and professional advocates in 1994 to determine their perceptions of Special Care Units in nursing homes as part of a study they conducted concerning Alzheimer SCUs. The Alzheimer's Association began the study "with the assumption that facilities claiming the label 'special care' should provide an environment and an array of services that are specifically tailored to meet the needs of persons with dementia and different from those provided for residents who are cognitively intact" (viii).

The study was conducted in two parts over a nine-month period.

Part I: survey of professional advocates to determine their overall perceptions of SCUs --112 state long term care ombudspersons and 61 directors of state agencies for nursing licensure from 29 states

Part II: survey of 453 family members who now have or had a family member in a SCU to determine their perceptions of SCUs

Major Findings:

1. Professional Advocates reported little differences between SCUs and traditional nursing homes.
2. One-third of families said they are paying more for SCUs; another one-third said they did not know if they were paying more.
3. Family members were satisfied with the care their loved ones received, and the overwhelming majority would place their loved ones in the same SCU again.
4. A majority of professional advocates favored the creation of rules governing operation and evaluation of SCUs.

Conclusions:

The trend for nursing homes to offer SCUs for persons with dementia often seems to be an expensive marketing strategy rather than a provision for the demented's needs.

Families need more information concerning the costs included in placing a loved one in a SCU.

Government regulation of SCUs would be a little "premature" at this stage of the development of SCUs.

Recommendations of the Study:

States should have disclosure legislation to require facilities to disclose the special services they provide and to include provisions and resources for consumer education and training of surveyors and ombudspersons.

Educational and training programs concerning caregiving should be available for families, state surveyors, ombudspersons, physicians, and other health care professionals.

Research should be conducted on the impact of SCUs, alternatives to SCUs, caregiving methods, and the value of specific programs (i.e., group therapy, music therapy).

CURRENT STATE POLICY DEVELOPMENTS

South Carolina

South Carolina does not currently have legislation governing the care of persons with Alzheimer's Disease and Related Disorders (ADRD). There has been some legislation within the state regarding ADRD, however. Under the auspices of the Appropriation Act, the Joint Health Care Planning and Oversight Committee in cooperation with the Joint Legislative Committee on Aging was directed to study the following as they related to Alzheimer's disease and related disorders: 1) State nursing home regulations; 2) State policies on financing and reimbursement of the costs of health care including respite care; and 3) Policy changes which would improve the care of patients. A report of the study was submitted to the committees in December, 1986 (Appropriation Act 540, Part I, Section 174, 1986).

In 1988, the General Assembly passed the Long Term Care Insurance Act (Code 38-72-10) which included some provisions for persons with ADRD. The regulations under the act state that long term care insurance cannot exclude coverage for Alzheimer's disease in addition to providing for continuation and conversion privileges, coverage for treatment whether it is received in the home or a facility, must contain an option for inflationary protection, and must prescribe a standard format and outline of coverage (SC Insurance Dept. Reg. 69-44, 1989).

In 1990, the Statewide Alzheimer's Disease and Related Disorders Registry was established (Code 44-36-10). The purpose of the registry is to collect data to evaluate the incidence and causes of ADRD, and also to provide data for research on ADRD (Appendix A).

In 1993, the Joint Legislative Committee on Aging was directed to form a Blue Ribbon Task Force to study the planning, coordination, and delivery of services to Alzheimer's victims and their families and to recommend an organizational structure to have primary responsibility for these functions and to report to the Committee by January 1, 1994 (Joint Resolution, Act 195). The report is entitled "The Gray Plague of the Twenty-First Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families and Caregivers." The report details the recommendations for future legislation that would provide for the needs of persons with ADRD.

In 1994, the Resource Coordination Center for Alzheimer's Disease was established (Code 44-36-310). The Resource Center is in the Division on Aging, Office of the Governor. The Center's purpose is to provide statewide coordination, service system development, information and referral, and caregiver support services. In 1994, \$100,000 was appropriated from state funds to the Resource Coordination Center for Alzheimer's Disease to assist local communities and persons who have ADRD and their families (Appropriation Act, Part I, Governor 6DD.45, 1994) (Appendix A).

In 1995, legislation to amend the Alzheimer's Disease and Related Disorders Registry statute has been introduced to the House (H. 3929) and the Senate (S. 703) (Appendix A). The amendments address a name change of the registry, access to available data, and an advisory committee in order to improve the accuracy of information.

The Joint Resolution (R23), passed in the 1995 Legislative Session, to study whether or not there is a need for special licensing criteria for care units that provide treatment and care for persons with Alzheimer's disease and related disorders is the first step South Carolina has taken to address the issue of how to regulate the care of this population by law.

Other State Laws and Regulations

The concern about the quality of care given to persons with Alzheimer's disease or related disorders is not unique to South Carolina. Evidently, the National Alzheimer's Association is concerned since they conducted the survey of families and professional

advocates (*Alzheimer Special Care in Nursing Homes: Is It Really Special?*). The National Alzheimer's Association has also created *State Policy Clearinghouse Issue Kit: Special Care Units*. The issue kit includes an issue overview, a policy statement, and model legislation. Due to the increasing awareness of Alzheimer's disease, the Association has been researching the need for special care of persons with ADRD and the necessary accompanying legislation in regards to the special care units. "With this growth has come a challenge for Alzheimer advocates concerned about the quality of care in those Units. Specifically, that challenge exists in designing proposals that protect consumers from unfounded claims of specialized care, while avoiding the burden of traditional regulations that could stifle or otherwise inhibit a developing field. One solution is to require facilities to disclose what is special about their program, thereby allowing consumers to make informed choices" (*Alzheimer's Association State Policy Clearinghouse*, 1994).

The following states have specific regulations concerning special care units: Colorado, Iowa, Kansas, New Jersey, North Carolina, Oregon, Tennessee, Texas, and Washington. Arkansas "has enacted legislation that mandates the eventual development of such regulations" (*Alzheimer Special Care in Nursing Homes: Is It Really Special?*, 1994, p. 1). The regulations generally detail the admission criteria, safety, staff training, and physical design.

Florida, Nebraska, and Rhode Island have enacted special care disclosure laws (Appendix B). "These laws require written disclosure for the special care features included at each facility promoting itself as a SCU. Disclosure statements must be issued to the public and to the appropriate state certification agency" (*Alzheimer Special Care in Nursing Homes: Is It Really Special*, 1994, p. 2). Disclosure means the organization which provides care for persons with ADRD must disclose to the consumer the type of care given, the admission criteria, the discharge procedure, staff's qualifications for caring for these patients, and the costs of the care.

The Alzheimer Association has adopted the following policy regarding special care disclosure:

"The Association supports the enactment of state legislation regarding the disclosure of claims made by facilities relative to their Alzheimer special care units. Such

disclosure requirements should conform to the *Guidelines for Dignity* and include provisions and resources for consumer education and training of surveyors and ombudspersons" (*Alzheimer Special Care in Nursing Homes: Is It Really Special?*, 1994, p. 25).

Nebraska and Rhode Island have modeled their regulations after the Alzheimer's Association's *Guidelines for Dignity*, which outlines eight goals for specialized care for persons with Alzheimer's.

Guidelines for Dignity

Goal 1: Philosophy

A specialized Alzheimer/dementia care program has a written statement of overall philosophy and mission which reflects the needs of residents afflicted with dementia.

Goal 2: Pre-Admission

There is an effective process, for placement in the program, by which diagnosis are verified, the needs of the person with dementia are assessed, involvement of family is recognized (to the desired extent of the individual family) and appropriateness of the facility is confirmed.

Goal 3: Admission

The person with dementia is admitted to the program in a convenient and supportive manner, and the family is able to complete the admission in a timely fashion.

Goal 4: Care Planning and Implementation

The plan of care and its implementation is resident oriented, flexible and inclusive of family; and it is intended to promote individual dignity, optimum health and well being and to maximize function of the person of dementia.

Care provision is the responsibility of the interdisciplinary team, committed to creating a living environment that enhances quality of life for residents and families.

Goal 5: Change in Condition

As the disease moves to late stages, the plan of care evolves and is responsive to changes in condition. A specialized program demonstrates commitment to assist families over the full course of the disease.

Goal 6: Staffing Patterns and Training

All staff, including administrators and non-direct staff (e.g. housekeeping, dietary, maintenance, volunteers) who work with residents and families in the specialized Alzheimer/dementia program receive the support of an ongoing training program.

Goal 7: Physical Environment

The physical environment and design features support the functioning cognitively impaired adult residents, accommodate behaviors and maximize functional abilities, promote safety and encourage independence of residents.

Goal 8: Success Indicators

The program is involved in efforts to evaluate the benefits of their specialized Alzheimer/dementia care.

Source: Alzheimer's Association. *Guidelines for Dignity*, (1992)

The National Alzheimer's Association has published a policy statement regarding special care disclosure:

"That the association support the enactment of state legislation regarding the disclosure of claims made by facilities relative to their Alzheimer Special Care units. Such disclosure requirements should conform to the Guidelines For Dignity and include proper enforcement and monitoring mechanisms. In addition, such legislation should include provisions

and resources for consumer education and training of surveyors and ombudsman" (*Alzheimer's Association: State Policy Clearinghouse*, 1994).

Also, the Alzheimer's Association has created a model act for Alzheimer Special Care Legislation. It promotes disclosure law. The act includes a broad definition of what an

Alzheimer Special Care Unit/Program is so that the variations of Alzheimer treatment will be covered by the act (Appendix C).

Staff training is a major issue in the area of care units for persons with Alzheimer's disease and related disorders. South Carolina has not passed any legislation in regards to this issue thus far. Illinois, since 1987, requires nurses' aides employed in nursing homes that admit persons with ADRD to complete 12 hours of in-house training in the care and treatment of these patients (P.A. 84-940, SB 147). By law since 1986, Maryland requires the Department of Health and Mental Hygiene and the Office on Aging to require specified related institutions and providers of sheltered housing for elderly to have in-service education programs on dementia and the management of dementia patients with regard to their physical, intellectual, and behavioral manifestations (MD Laws, Chap. 634, HB 175/SB 142). In 1988, Missouri revised their requirements for regulating and monitoring services provided by long-term care facilities handling patients with Alzheimer's disease and other mental disorders to add 45 classroom hours to training requirements for nursing assistants working in nursing homes.

DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL

Facility Licensing Process

Whenever licensing a health care facility or health and safety standards are an issue in South Carolina, the Department of Health and Environmental Control (DHEC) is the authorized agency responsible for the licensing process. DHEC licenses inpatient care facilities (including nursing homes and hospitals), community residential care facilities, and outpatient and home care. DHEC will be responsible for the study on whether or not there should be special licensing criteria for care units for persons with Alzheimer's disease or related disorders. If the results of the study indicate a need for special licensing criteria, DHEC will also be responsible for the development of the criteria in consultation with other interested organizations. Currently, the only regulations these units must adhere to are those

for nursing homes or day care facilities for adults. However, the regulations are geared towards the residents of these facilities who *do not* have ADRD as a primary diagnosis, and therefore, the regulations for care are not inclusive of the special considerations necessary for persons with ADRD.

DHEC is a large agency responsible for public health and environmental protection. The department is divided into five deputy commissionerships, one being the Office of Health Regulations. The Office of Health Regulations is subdivided into various divisions, many of which are involved in the licensing process. There are three divisions primarily responsible for continuing care facilities.

The first of these, the Certificate of Need (CON) Division, reviews certificate applications for facilities to determine their conformance with the State Health Plan and the need for additional units in a geographic area. If need is demonstrated, then a Certificate of Need is issued to the applicant. There are exemptions from the CON requirement: continuing care retirement communities (CCRC), day care for adults, and residential care facilities.

The next step is for the second division, the Division of Health Licensing, to send regulations, application for license, list of prerequisites, inspection guide, and other pertinent information to the potential licensee. That particular step will include the criteria for dementia care units if such requirements are passed. However, if construction or renovation is also required for licensing, then coordination between CON and the Division of Health Facilities Construction must occur before Health Licensing sends the information to the applicant. The Division of Health Licensing must receive an affidavit of completion from the Division of Health Facilities Construction before proceeding with the licensing process.

After all of the before mentioned steps in the licensing process are met, DHEC must conduct the initial licensing inspection. If the facility meets the licensing standards, DHEC will advise the administrator of the date the license will become effective. The following steps apply if the facility does not meet the standards and after the advisement of when the license will be effective. DHEC will give an on-site report of inspection, and then prepare and mail the report of the visit to the facility administrator. The deficiencies must be corrected before the license will be issued to the facility. Following licensing approval, the

facility will be included in the licensing schedule of DHEC. DHEC will conduct annual inspections according to their schedule. The facility must prepare for the annual inspection and pass it in order to remain licensed by DHEC.

If licensing care units for persons with Alzheimer's disease and related disorders becomes a law, then the licensing criteria for such units would be developed through regulations by DHEC and added to the current licensing standards for nursing homes and adult day care facilities desiring these units. The development of regulations normally takes 12 to 18 months and must be approved by the legislature. Then, any facility with an ADRD unit must meet the criteria by the effective date of the regulations in order to remain licensed.

Extraneous Variables in DHEC Licensing Process

With the possibility of additional regulations, the political atmosphere may become heavy with complaints and concerns targeted at the Department of Health and Environmental Control. Currently, the norm among people is a distrust in big government. The perception is the more government regulations, the bigger government is. DHEC is an extension of state government. Therefore, when regulations are established by law, South Carolinians may become distressed by the expansion of government into their private lives. Thus, the public response to additional standards of care may be a risk the establishment of licensing criteria for care units for persons with Alzheimer's disease and related disorders.

The likelihood of increased costs of health care as a result of implementing more regulation on the nursing homes and adult day care industries in South Carolina could be a deterrent for some interested parties. Requiring more standards of patient care in licensed facilities can impact costs of state government, taxpayers/consumers, and/or the nursing homes and adult day cares. Who incurs that cost depends on the number and complexity of the potential criteria for ADRD units. For example, if the criteria simply involve a limited increase in inspection efforts for DHEC, then the cost of expanding the required facility inspections will be nominal in comparison to the cost that would incur if the criteria

demanded a significant increase in inspection time. DHEC may have to hire additional inspectors to cover these increased demands. If criteria require facility owners to renovate facilities, then the capital expenditures of facilities will increase as well. Also, staffing costs may rise as a result of the regulations.

Within the link between state government, health care facilities, and the taxpayers (consumers), cost shifting occurs to balance the expense of new and expanded services. When the government budget increases, it must take funds from somewhere to cover the cost of expansion. Therefore, if the cost of DHEC facility inspections increases due to additional complex criteria for ADRD care units, then the facilities may have to pay the government through increased fees to make up for the resources allocated to inspect and enforce the criteria. Consequently, the facilities (nursing homes/adult day cares) must then determine how to replace the funds lost to state government to remain licensed. The likely choice for the facilities to finance the increased costs of maintaining their licenses to operate will be the consumers. To sum up, if the state government's budget increases to maintain or expand a service, then the service costs are likely to increase as well. When the service costs increase, then the service will probably secure funds from its consumers to reimburse the industry. Therefore, the taxpayer (consumer) will actually be paying the government to maintain its licensed facilities by way of the facilities themselves. Once again, the complexity of the regulations determines their subsequent costs.

There are opposing theories concerning whether or not regulations for dementia care would restrict innovative and creative treatment. Some interested parties assert that the regulations must be worded in a way that will not allow debate on how to follow the regulations. Subsequently, innovative opportunities would be eliminated from the care providers' repertoire of treatments. The opposition argues that the regulations should be flexible enough to allow creativity while still providing guidelines. There are issues that will require stricter regulations and others which would need flexible wording in order to provide individualized care for persons with Alzheimer's disease. For example, staff training is an issue that necessitates direct instructions, and the issue of activity planning perhaps should be standardized for dementia residents to accommodate each of their needs and the structure that persons with dementia typically require for optimal functioning. What must remain at the

forefront of the interested parties' mission is the consumer. Developing and implementing regulations regarding the care and treatment of individuals with ADRD should be done in their best interest first.

Potential Licensing Requirements of ADRD Care Units

Some areas of potential licensing requirements of ADRD care units are in staff training, admission criteria, safety, physical design, and cost of care. Some thoughts on these issues follow with the stipulation that there are still more considerations and possibilities than those that are suggested.

STAFF TRAINING

Who would provide the training for the staff of the ADRD unit? How much would the training cost? Who would pay for the training? What should be the training criteria for ADRD unit staff positions?

Currently, the Department of Health and Environmental Control requires staff to have annual training on subjects such as infection control, resident rights, fire safety, transfer, etc., but there is no required training on Alzheimer's disease. The Statewide Alzheimer's Advisory Committee in the Division on Aging, Office of the Governor recently conducted a survey of long term care facilities in South Carolina to determine the amount of Alzheimer's training that is given to their staff. The return rate of the survey was 70%, and the rate of no Alzheimer's training provided to staff in long term facilities is 40%. One training option is the training manual and video "Alzheimer's 101." This video and manual were put together by South Carolina Educational Television and the Division on Aging (called the Commission on Aging at the time of the video and manual's publication). "Alzheimer's 101" provides staff, family, and friends with optimal training at minimal cost. There are 150 certified trainers across South Carolina. Access to the training can be sought through local Area

Agencies on Aging (AAA). The AAAs can inform interested persons of locations and dates of training sessions. Generally, the Alzheimer's Association chapters in the state sponsor the training classes or seminars at various facilities within the community. The cost of training is for the manual. "Alzheimer's 101" has won national awards, and it has also been bought by aging agencies in other states for their own Alzheimer's care and treatment training. The video and manual are currently being updated to include two more chapters on working with difficult behaviors and stress of caregivers.

ADMISSION CRITERIA

What admission criteria should be considered for an ADRD care unit?

Being ambulatory is characteristic of persons on an Alzheimer's unit. Once the individual with ADRD deteriorates to the point of being bed bound or wheel chair bound as a result of the disease affecting their psychomotor coordination, the person is generally moved to a skilled nursing unit. ADRD units usually want to screen out psychotic elderly. The behaviors of a person affected by psychosis and a person victimized by dementia can be similar, however, the treatment for the separate illnesses are not necessarily the same. A psychotic person will disrupt and distress persons with Alzheimer's due to the nature of their obtrusive behavior.

PHYSICAL DESIGN

What special construction if any should be required of an ADRD unit? Should certain colors and patterns be avoided for the decor? Should the environment be home-like? Should there be a walking area for wandering behavior? Should sight of the parking lot be camouflaged? Should the rooms be furnished or unfurnished? Should soothing music be available during the day hours? Would any special equipment be necessary?

In units that provide treatment for ADRD residents, wandering behavior needs to be accommodated. In addition to constructing an adequate environment for wandering, the decor should have a calming effect through the use of soft colors and no busy patterns on the

walls. A home-like environment with residents' own belongings seems to have a positive effect. Cues in the dementia unit have also had success for residents and staff, such as identifying signs at bathroom doorways and shadow boxes outside of the residents' rooms with personal objects and pictures. A problem for residents in dementia units is wanting "to go home." Therefore, when the residents see the parking lot filled with cars, they generally become insistent and agitated about going home. Clouded glass in areas where the parking lot is in view can alleviate that source of anxiety. Soft slow music tends to have a calming effect on ADRD residents as well.

SAFETY

What precautions should be taken to avoid the possibility of residents endangering their own health? Should there be locks on the unit exits? How safe are adjoining yard areas?

Persons with ADRD have distorted reasoning. Their thinking is damaged by the disease. Behaviors such as putting objects in their mouths, burning themselves and their environment when smoking, and burning themselves with scalding hot water are typical of repercussions of their lack of reasoning. Safety precautions are necessary for the protection of persons with dementia. Staff must begin by being watchful and aware of the risky habits of their residents.

COST OF CARE

Should the care and treatment of persons with ADRD be priced separately from the care of the acute and other long term care residents? If so, what criteria would justify the difference in cost?

The cost of a unit specific to persons with Alzheimer's disease and related disorders should be disclosed to the consumer before the admission process begins. The cost of the unit should also have expense justification to accompany the information (i.e., special services available to resident in addition to routine services).

REVIEW OF STUDIES ON DEMENTIA SPECIFIC OR SPECIAL CARE UNITS

Nebraska Alzheimer's Study

Nebraska Governor's Alzheimer's Disease Task Force formed a special subcommittee to study the appropriate standards for ADRD special care units and recommend legislation to ensure the proper care is given in these units. The task assigned to the subcommittee is the same as the task legislated to the Department of Health and Environmental Control in South Carolina this legislative session. In 1989, the subcommittee completed the report "Special Care Units For Persons With Alzheimer's Disease."

Like South Carolina, the challenge for the Nebraska subcommittee was "there are no standards against which to monitor their quality. Families are left to their own devices in determining whether a special care unit is providing optimum care for their family member with Alzheimer's Disease" (Subcommittee Report, 1989, p. 2). They had five major recommendations:

- Department of Health should prepare regulations within the statutes based on the subcommittee report, Iowa's law regulating special care units, and Standards for Intermediate Care Facilities - Mental Retardation Center.
- The units should be described with a name that includes all dementia disorders: Special Care Unit for Dementing Disorders or Illnesses
- Staffing ratios should be based on acuity ratings of the patients (shown to be successful in psychiatric units).
- Medicaid should provide reimbursement which is also based on acuity ratings of the patients and additional standards required (extra requirements for special care units, such as pre-admission testing, special staff training, environmental alterations, provision of appropriate activities, family support, and higher staffing levels).
- Regulations must be written with the concern that standards for special care units could raise rates for private-pay patients beyond their means.

The Nebraska Governor's Alzheimer Disease Task Force subcommittee report on "Special Care Units For Persons With Alzheimer's Disease" and a description of the policies and procedures for special care units, training program for staff, physical standards for special care units, and subcommittee's bibliography is Appendix D.

National Resource Center on Alzheimer's Disease
Suncoast Gerontology Center
University of South Florida

The National Resource Center at the University of South Florida developed "Guidelines for Dementia Specific Care Units (DSCUs) for Memory Impaired Older Adults." "The guidelines are intended to *assist* in the organization and implementation of special care units and should not be regarded as definitive criteria for licensing or regulating such units" (Cairl, 1991, p. 2). The guidelines are broken down into several conceptual categories:

- Therapeutic Goals and Philosophy of DSCUs
- Target Population
- Admission/Discharge
- Assessment and Follow-up Procedures
- Physical Environment
- Activities
- Unit Size and Staffing
- Staff Training
- Family Involvement
- Evaluation

A brief summary of these are:

The guidelines emphasize providing memory impaired adults with a "safe, humane, and minimally restrictive " environment (Cairl, 1991, p. 7). Also, the range of needs of the patient should be considered when targeting, admitting, and discharging him or her.

Awareness of the residents' functional level and accompanying care provision must be on-going. The environmental conditions and/or therapeutic activities should not be "overly

stimulating and confusing" (Cairl, 1991, p. 13). The guidelines suggest utilizing a small unit with its own unit director, activities director, and plenty of staff. Intensive and routine training is proposed for the DSCU staff. The involvement of families and friends in the care of the residents would be beneficial. Lastly, the guidelines support on-going systematic evaluation of DSCUs and their respective operations (Appendix E).

Evaluating the Physical and Caregiving Environment of Alzheimer's Disease and Special Care Units University of North Carolina at Chapel Hill

Dr. Philip Sloane, Professor of Family Medicine and Epidemiology, at University of North Carolina at Chapel Hill conducted a study on the physical and caregiving environmental needs of persons with Alzheimer's Disease in special care units in 1993. Dr. Sloane evaluated and tested many variables in the study including:

- Relationship of unit to nursing station
- Disguising exits
- Homelike quality of public areas
- Outdoor courtyards in SCUs
- Kitchen appliance availability on SCUs
- Directional cues in public areas
- Light levels in unit
- Noise levels in unit (noxious and human)
- Provision of privacy in shared rooms
- Tactile stimulation
- Planned activities

There are several more variables which were studied in addition to the above mentioned. A description of the rationale for each variable is provided along with the current statistics on the provision of each variable (Appendix F).

National Institute on Aging

The National Institute on Aging has been conducting several collaborative studies on special care units for Alzheimer's disease. A description of the projects, published February 1994, is provided in the Appendix G.

Dementia Care Unit Site Visits Columbia, South Carolina

Dana Blanton, Legislative Intern, with the Joint Legislative Committee on Aging, South Carolina General Assembly, made four site visits to health care facilities in the Columbia area to gather data on the current care and treatment of Alzheimer's disease and related disorders. The site visits were made in February 1995. A meeting was arranged with an administrative staff member at each facility for discussion and a facility tour. The information was gathered according to the following objectives:

- (1) Determine the number of staff to residents.
- (2) Determine the required training of the staff.
- (3) Determine how wandering behavior is dealt with by the facility's staff.
- (4) Learn the philosophy of the organization regarding the care of ADRD residents.
- (5) Determine the environmental accommodations made for ADRD residents.
- (6) Determine the cost variations within the facility (i.e., Alzheimer unit vs. other units)
- (7) Determine whether or not the organization advertises special care for persons with ADRD.
- (8) Determine how the facility deals with varying levels of care for persons with ADRD.
- (9) Learn how the representative of the facility feels about the study on special licensing criteria for persons with ADRD.

A brief description of the information gathered from each visit follows:

National Healthcare Center of Lexington, South Carolina

National Healthcare does not currently have a unit specific to persons with ADRD.

However, NHC does admit people with dementia. The demented population at NHC is in a small minority at this time, therefore, there has not yet been a move towards accommodating the range of needs of a person with ADRD, although NHC does utilize the Wanderguard System, which is a bracelet worn by residents that is electronically connected to the locks on the exits of the building and an alarm system. The bracelet is worn on either the wrist or the ankle. There are electric fields or sensors around the exits that sound an alarm when the resident approaches. If the resident keeps pushing on the door for 15 seconds, then the door will automatically unlock (for fire and safety reasons). The fifteen seconds gives the staff enough time to reach the resident and get him or her away from the door. The Wanderguard System is the only real response to the behavior demonstrated by persons with dementia at NHC. According to the administration, NHC will be assessing the need to integrate care and treatment for persons with ADRD as a part of their organization.

Life Care Center of Columbia

As advertised in the organization's information packet, Life Care Center's Alzheimer's services include:

- 24-bed secure unit with adjoining courtyard
- Specially trained care technicians under the direction of the program coordinator
- Extensive, personalized activity programs and behavioral management
- Support staff available for pre-admission assessment
- Private dining
- Private activities

All new staff at Life Care go through a one week training session/orientation, which includes an introduction to Alzheimer's disease and related disorders. There are monthly in-services at which the training video "Alzheimer's 101" has been shown to the Alzheimer unit staff. The Alzheimer's Association has done some workshops for the staff as well. The facility also has resources in their activities director and their social worker due their experience in working with ADRD patients.

The cost of living in the Alzheimer unit is more expensive than that of the other units in Life Care Center. The justification is the unit does offer special care for its residents in addition to the common amenities of the facility.

South Carolina Episcopal Retirement Community at Still Hopes

Within the information packet, Still Hopes asks and answers the question "What makes Special Care Center unique or different?"

- All residents diagnosed with Alzheimer's or related disorder
- Higher ratio of staff to residents
 - results in higher quality of care
 - staff specially selected and trained to deal with cognitively impaired
- Provide assisted independence to maintain residents at their highest functioning level
- Stable, well-secured home-like environment for safety and independence
- Program designed around individual needs of resident
- Greater family satisfaction, support and involvement (participation in care plan and daily activities)
 - special training/education for caregivers
- Activities off campus (restaurants, music programs, church service)
- No physical or chemical restraints
- Improved nutrition by increased reminding, cuing
 - special diet provided upon doctor's order
- Provide adult day care for those living with families
- Provides short-term respite care for caregivers
- Alzheimer Support Group available to family members and the community

The cost of living in the Alzheimer Special Care Pavilion is more than the cost of the other units at Still Hopes with the exception of the skilled unit which costs the same monthly in addition to a \$7000 entrance fee, which all residents on the Still Hopes campus must pay at the time of admission.

The Lowman Home

Care for persons with Alzheimer's disease and related disorders is provided in a secured unit, called Bethany, in the skilled nursing center. The fees for the secured unit are the same as the skilled nursing unit fees. General services offered by the skilled nursing unit are also offered to the ADRD unit. Services for the unit specific to ADRD residents include:

- 44-bed secure unit
- Unit Director
- High nursing staff ratio
- Private dining
- Individualized structured activities
- Secure, outside wandering area
- Family involvement in care planning and activities
- *B-Team* group activities available to alert ADRD residents
- Music therapy

The Bethany staff go through the "Alzheimer's 101" training at the time of placement. There are regular in-services for the Bethany staff. Stress relief training is an important part of the staff's education. When the general staff of The Lowman Home goes through orientation, an overview of Alzheimer's disease is given by the Bethany Unit Director.

Pros and Cons of Dementia Specific or Special Care Units

What could possibly be wrong with offering special care to persons with such a complicated disease as Alzheimer's disease or related disorders? The unique characteristics of the disease require much accommodation in terms of care, so finding fault with efforts to provide distinctive supervision is difficult. The real issue seems to lie with *standards* of care. Should those be mandated to ADRD care providers? That is the crux of the study that will be conducted in South Carolina by the Department of Health and Environmental Control.

Some *Pros* of DSCUs include:

- (1) Closed environment and reduced stimulation
- (2) Atmosphere of freedom and openness (with security)

- (3) Structured and individualized activities
- (4) Reduced physical and chemical restraints
- (5) Knowledgeable staff

Some *Cons* of DSCUs include:

- (1) Cost of care to consumers and facilities
- (2) Potential legislative restrictions on innovation of care
- (3) Stress level of staff (if not attended to by administration)
- (4) Lack of established standards of care and staff training

There are numerous interested parties in the process and outcome of the study on whether or not there should be specific criteria for care units for persons with Alzheimer's disease and related disorders. In spite of the weaknesses of dementia specific care units, most of the concerned persons are most likely willing to find optimal ways to standardize the care and treatment of persons with ADRD or at least to require care provider disclosure to consumers to allow them to make more informed decisions about where to place their loved ones who are afflicted with this burdensome disease.

INTERESTED PARTIES IN JOINT RESOLUTION

Families/Caregivers

The families/caregivers of victims of Alzheimer's disease or related disorders naturally want their loved one to receive the best possible care for their unique problems. As consumers, families/caregivers should be confident that facilities which allegedly offer special care to ADRD residents actually service this particular community well.

Department of Health and Environmental Control

The importance of DHEC's role in the Joint Resolution is obvious since they will be conducting the study, and they are the licensing authority of health care facilities in South Carolina. DHEC is in support of the study.

Division on Aging, Governor's Office

The mission of the Division on Aging is to enhance the lives of the aged population in South Carolina. Thus, it supports research that may influence the advancement of their target population. Also, the Alzheimer's Resource Coordination Center, under the authority of the Division, would certainly want to continue to advocate for the improvement of care and treatment of individuals with Alzheimer's disease or related disorders.

Joint Legislative Committee on Aging

The Committee on Aging as sponsors fully support the Joint Resolution. It is their desire for their constituency's needs to be well known and serviced in the best way possible.

Blue Ribbon Task Force on Alzheimer's Disease

The Joint Resolution came out of the Task Force's recommendations in the "Gray Plague of the Twenty-First Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families, and Caregivers." The completion of the study and the utilization of its results will bring some satisfaction and closure to the Task Force's work.

American Association of Retired Persons

The AARP's agenda is always to help meet the needs of its membership. Due to Alzheimer's disease and related disorders being an increasingly prevalent condition among the elderly, they are behind the improvement of the care and treatment of persons afflicted with this disease.

South Carolina Health Care Association

The SCHCA includes the nursing home industry. The Association supports the study legislated through the Joint Resolution. However, their interest in the outcome of the study is likely to be two-fold. One, the industry surely wants to serve their clientele better than their competitors. Second, cost is an issue in regards to implementing potentially expensive regulations.

South Carolina Non Profit Homes for the Aged

SCNPHA supports research on the necessary care and treatment of persons with Alzheimer's disease and related disorders as well, since they service such persons in their homes. A potential concern of their's will be required expenditures for such care.

Adult Day Care Association

Many adult day care centers in South Carolina work with persons with Alzheimer's disease and related disorders. Therefore, they in addition to the before mentioned organizations desire to meet the needs of these consumers. Cost is likely to be an issue for the Adult Day Care Association.

Alzheimer's Association

The Alzheimer's Association's interest in the DHEC study is definitely conspicuous. One might venture to perceive the study as an extension of the Association's mission: to help victims of Alzheimer's disease and related disorders to function successfully at every stage of their affliction.

CONCLUSION

The projection of the prevalence of Alzheimer's disease and related disorders among the 65+ population in South Carolina as well as in the United States is a forewarning of the necessary analysis and program planning for servicing the victims of ADRD and their caregivers. Research of the physiological and environmental variables of the disease should continue until scientists have uncovered the disease's mysterious etiology. Studies on the most effective care and treatment for the behaviors and other symptoms associated with the disease should persevere for the creation of innovative programs and policies. The more professional advocates and the families and friends of the persons with ADRD understand about the course of the disease, physiologically and functionally, the better armored they will be for overcoming their fears of the illness and the frustration that accompany care provision of the disease's prey.

The course of the legislative process in South Carolina regarding the study on whether or not there should be specific licensing criteria for facilities which provide care units for Alzheimer's patients and other specialized programs for individuals with Alzheimer's and other related disorders will be a consequential one. The study, done by the Department of Health and Environmental Control in consultation with the Alzheimer's Disease and Related Disorders Resource Coordination Center, Division on Aging, Office of the Governor and with representatives of homes for the aging and the nursing home industry, will be influential on the legislators of South Carolina in their decision-making process in respect to enacting laws which would govern the care and treatment of persons with ADRD in certain settings. Concerned South Carolinians should be watchful and in touch with their legislators about making the best decisions for the consumers of ADRD services in addition to the service providers.

Research shows that there are many variables to be considered when attempting to provide optimal care to persons with ADRD. As the studies done by the National Alzheimer's Association, Nebraska, University of South Florida, University of North Carolina at Chapel Hill, and the National Institute on Aging demonstrate, the influences on

successful care provision are numerous. The results of these studies and similar research projects will be beneficial to individuals and organizations who are currently researching or in the planning stages of researching potential standards of care for persons with Alzheimer's disease and related disorders.

APPENDIX A

CHAPTER 36 [New]

Alzheimer's Disease and Related Disorders

	Beginning Section
ARTICLE 1. STATEWIDE ALZHEIMER'S DISEASE AND RELATED DISORDERS REGISTRY	44-36-10
ARTICLE 3. ALZHEIMER'S DISEASE AND RELATED DISORDERS RESOURCE COORDINATION CENTER	44-36-310

ARTICLE 1 [New]

STATEWIDE ALZHEIMER'S DISEASE AND RELATED DISORDERS REGISTRY

- SEC.
44-36-10. Establishment; information collected; purpose.
44-36-20. Advisory committee; membership; duties.
44-36-30. Confidentiality.

Editor's Note—

1994 Act No. 326, § 2, eff April 20, 1994, provides as follows:
"SECTION 2. Chapter 36, Title 44 is retitled 'Alzheimer's Disease and Related Disorders' and Sections 44-36-10 through 44-36-30 are designated as Article 1 of Chapter 36, Title 44 and entitled 'Statewide Alzheimer's Disease and Related Disorders Registry'."

§ 44-36-10. Establishment; information collected; purpose.

There is established the Statewide Alzheimer's Disease and Related Disorders Registry. Each hospital, clinic, individual practitioner, or other agency or facility providing health care may participate in this registry by making available to the School of Public Health, University of South Carolina, abstracts of its records of patients who have been diagnosed as having Alzheimer's disease or a related disorder, after receiving a written authorization from the patient or other legally responsible party for the release of the information. These abstracts may include the name, address, sex, race, and any other pertinent identifying information regarding each patient.

From the abstracts received, the School of Public Health shall establish and maintain a Statewide Alzheimer's Disease and Related Disorders Registry. The purpose of the state registry includes, but is not limited to:

- (1) collecting data to evaluate the incidence and causes of Alzheimer's disease and related disorders;
- (2) providing data to support research on Alzheimer's disease and related disorders.

HISTORY: 1990 Act No. 532, § 1, eff July 1, 1990.

§ 44-36-20. Advisory committee; membership; duties.

The School of Public Health shall appoint an advisory committee to assist in maintaining this registry which must include, but is not limited to, the Directors of the Department of Mental Health and the Department of Disabilities and Special Needs or their designees and one representative of each of the following

groups: practicing physicians treating patients with Alzheimer's disease and related disorders, clinical psychologists evaluating and treating patients with Alzheimer's disease and related disorders, neuropathologists, researchers engaged in clinical investigations related to dementias, basic science researchers engaged in studies related to dementias, nursing home administrators, the Medical University of South Carolina, and the University of South Carolina Medical School. The advisory committee shall assist the School of Public Health in developing protocols, choosing necessary psychometric validation instruments, and other technical mechanisms.

HISTORY: 1990 Act No. 532, § 1, eff July 1, 1990; 1993 Act No. 181, § 1101, eff July 1, 1993.

Effect of Amendment—

The 1993 amendment substituted "Directors" for "Commissioners", and "Disabilities and Special Needs" for "Mental Retardation".

§ 44-36-30. Confidentiality.

The School of Public Health and all persons to whom data is released shall keep all patient information confidential. No publication of information, biomedical research, or medical data may be made which identifies the patients. However, the School of Public Health may contact the families and physicians of patients diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide them with information about available public and private health care resources.

The School of Public Health also may distribute any protocols or other materials provided by the advisory committee to practicing physicians and clinical psychologists.

HISTORY: 1990 Act No. 532, § 1, eff July 1, 1990.

ARTICLE 3 [New]

ALZHEIMER'S DISEASE AND RELATED DISORDERS RESOURCE COORDINATION CENTER

- SEC.
44-36-310. Alzheimer's Disease and Related Disorders Resource Coordination Center created; purpose.
44-36-320. Duties of Center.
44-36-330. Advisory council; membership; compensation of members.

§ 44-36-310. Alzheimer's Disease and Related Disorders Resource Coordination Center created; purpose.

There is created in the Office of the Governor, Division on Aging, the Alzheimer's Disease and Related Disorders Resource Coordination Center to provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families, and caregivers.

HISTORY: 1994 Act No. 326, § 1, eff April 20, 1994.

§ 44-36-320. Duties of Center.

The center shall:

- (1) initiate the development of systems which coordinate the delivery of programs and services;

- (2) facilitate the coordination and integration of research, program development, planning, and quality assurance;
- (3) identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
- (4) serve as a resource for education, research, and training and provide information and referral services;
- (5) provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
- (6) recommend public policy concerning Alzheimer's Disease and related disorders to state policymakers;
- (7) submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

HISTORY: 1994 Act No. 326, § 1, eff April 20, 1994.

§ 44-36-330. Advisory council; membership; compensation of members.

(A) The Alzheimer's Disease and Related Disorders Resource Coordination Center must be supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

- (1) Alzheimer's Association Chapters;
- (2) American Association of Retired Persons;
- (3) Clemson University;
- (4) Department of Disabilities and Special Needs;
- (5) Department of Health and Environmental Control;
- (6) Department of Mental Health;
- (7) Department of Social Services;

[Until July 1, 1995, paragraph (8) reads as follows:]

- (8) Health and Human Services Finance Commission;

[From and after July 1, 1995, paragraph (8) reads as follows:]

- (8) Department of Health and Human Services.
- (9) Medical University of South Carolina;
- (10) National Association of Social Workers, South Carolina Chapter;
- (11) South Carolina Adult Day Care Association;
- (12) South Carolina Association of Area Agencies on Aging;
- (13) South Carolina Association of Council on Aging Directors;
- (14) South Carolina Association of Nonprofit Homes for the Aging;
- (15) South Carolina Association of Residential Care Homes;
- (16) South Carolina Health Care Association;
- (17) South Carolina Home Care Association;
- (18) South Carolina Hospital Association;
- (19) South Carolina Medical Association;
- (20) South Carolina Nurses' Association;
- (21) Statewide Alzheimer's Disease and Related Disorders Registry;
- (22) University of South Carolina;
- (23) South Carolina State University.

(B) Members of the advisory council are not entitled to mileage, per diem, subsistence, or any other form of compensation.

HISTORY: 1994 Act No. 326, § 1, eff April 20, 1994; 1994 Act No. 326, § 3, eff July 1, 1995.

Editor's Note—

1994 Act No. 326, § 3, eff July 1, 1995, provides as follows:

"SECTION 3. The Code Commissioner is directed to change the reference to the 'Health and Human Services Finance Commission' in Section 44-36-330(8), as added by Section 1 of this act, to the 'Department of Health and Human Services', effective July 1, 1995."

Effect of Amendment—

The 1994 amendment by § 3, in paragraph (8), changed "Health and Human Services Finance Commission" to "Department of Health and Human Services".

H. 3929/S. 703

A BILL

TO AMEND TITLE 44, CHAPTER 36, ARTICLE 1, AS AMENDED, CODE OF LAWS OF SOUTH CAROLINA, 1976, RELATING TO THE STATEWIDE ALZHEIMER'S DISEASE AND RELATED DISORDERS REGISTRY, SO AS TO REVISE THE COMPOSITION OF THE ADVISORY COMMITTEE TO THE REGISTRY, TO PROVIDE FOR THE DUTIES OF THE COMMITTEE, TO REVISE THE CONFIDENTIALITY PROVISIONS, AND TO PROVIDE PENALTIES.

Be it enacted by the General Assembly of the State of South Carolina:

SECTION 1. Title 44, Chapter 36, Article 1 of the 1976 Code, as last amended by Act 181 of 1993, is further amended to read:

"Article 1

Statewide Alzheimer's Disease and Related Disorders Registry

Section 44-36-10. (A) There is established within the University of South Carolina School of Public Health the Statewide Alzheimer's Disease and Related Disorders Registry to provide a central information data base on individuals with Alzheimer's Disease or related disorders to assist in the development of public policy and planning. ~~Each hospital, clinic, individual practitioner, or other agency or facility providing health care may participate in this registry by making available to the School of Public Health, University of South Carolina, abstracts or its records of patients who have been diagnosed as having Alzheimer's disease or a related disorder, after receiving a written authorization from the patient or other legally responsible party for the release of the information. These abstracts may include the name, address, sex, race, and any other pertinent identifying information regarding each patient.~~

~~(B) From the abstracts received, the School of Public Health shall establish and maintain a Statewide Alzheimer's Disease and Related Disorders Registry. The purpose of functions of the state registry includes include, but is are not limited to:~~

~~(1) collecting data to evaluate the incidence and causes prevalence of Alzheimer's disease and related disorders in South Carolina;~~

~~(2) providing information for policy planning purposes; and~~

~~(2)(3) providing nonidentifying data to support research on Alzheimer's disease and related disorders.~~

~~(C) In gathering data the registry shall rely upon, to the extent possible, data from existing sources; however, the registry may contact families and physicians of persons reported to the registry for the purpose of gathering additional data and providing information on available public and private resources.~~

Section 44-36-20. (A) The School of Public Health shall appoint an advisory committee to assist in maintaining this registry which must include, but is not limited to, ~~the Directors of the Department of Mental Health and the Department of Disabilities and Special Needs or their designees and one representative of each of the following groups: practicing physicians treating patients with Alzheimer's disease and related disorders, clinical psychologists evaluating and treating patients with Alzheimer's disease and related disorders, neuropathologists, researchers engaged in clinical investigations related to dementias, basic science researchers engaged in studies related to dementias, nursing home administrators, the Medical University of South Carolina, and the University of South Carolina Medical School. The advisory committee shall assist the School of Public Health in developing protocols, choosing necessary psychometric validation instruments, and other technical mechanisms a representative of:~~

~~(1) South Carolina Alzheimer's Association chapters;~~

~~(2) American Association of Retired Persons, South Carolina~~

~~Chapters;~~

~~(3) Clemson University;~~

~~(4) Department of Disabilities and Special Needs;~~

~~(5) Department of Health and Environmental Control;~~

~~(6) Department of Mental Health;~~

~~(7) Department of Social Services;~~

~~(8) Department of Health and Human Services;~~

~~(9) Medical University of South Carolina;~~

1 (10) National Association of Social Workers, South Carolina
2 Chapter:
3 (11) South Carolina Adult Day Care Association;
4 (12) South Carolina Association of Area Agencies on Aging;
5 (13) South Carolina Association of Council on Aging Directors;
6 (14) South Carolina Association of Nonprofit Homes for the
7 Aging;
8 (15) South Carolina Association of Residential Care Homes;
9 (16) South Carolina Health Care Association;
10 (17) South Carolina Home Care Association;
11 (18) South Carolina Hospital Association;
12 (19) South Carolina Medical Association;
13 (20) South Carolina Nurses' Association;
14 (21) Alzheimer's Disease and Related Disorders Resource
15 Coordination Center, Office of the Governor, Division on Aging;
16 (22) University of South Carolina;
17 (23) South Carolina State University.
18 (B) The advisory committee shall assist the registry in:
19 (1) defining the population to be included in the registry
20 including, but not limited to, establishing criteria for identifying
21 patient subjects;
22 (2) developing procedures and forms for collecting, recording,
23 analyzing, and disseminating data;
24 (3) developing protocols and procedures to be disseminated to
25 and used by health care providers in identifying subjects for the
26 registry;
27 (4) developing procedures for approving research projects or
28 participation in research projects.
29 (C) Members of the advisory committee are not entitled to
30 mileage, per diem, subsistence, or any other form of compensation.
31
32 Section 44-36-30. (A) The School of Public Health and all
33 persons to whom data is released shall keep all patient information
34 confidential. No publication of information, biomedical research, or
35 medical data may be made which identifies the patients. However,
36 the School of Public Health may contact the families and physicians
37 of patients diagnosed as having Alzheimer's disease or a related
38 disorder to collect relevant data and to provide them with information
39 about available public and private health care resources.
40 The School of Public Health also may distribute any protocols or
41 other materials provided by the advisory committee to practicing
42 physicians and clinical psychologists.

1 (B) Except for use in collecting data on deaths from the Bureau of
2 Vital Statistics, Department of Health and Environmental Control, no
3 identifying information collected or maintained by the registry may be
4 released unless consent is obtained from the subject or the subject's
5 legal representative.
6

7 Section 44-36-40. Neither the registry or the School of Public
8 Health nor a person, medical facility, or other organization providing
9 or releasing information in accordance with this article may be held
10 liable in a civil or criminal action for divulging confidential
11 information unless the person or organization acted in bad faith or
12 with malicious purpose.
13

14 Section 44-36-50. The registry shall submit an annual report to
15 the Office of the Governor, Division on Aging, Alzheimer Disease
16 and Related Disorders Resource Coordination Center; the Department
17 of Health and Environmental Control; and the Budget and Control
18 Board, Division of Research and Statistics, Health Statistics."
19

20 SECTION 2. This act takes effect upon approval by the Governor.
21

-----XX-----

A JOINT RESOLUTION TO DIRECT THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL TO STUDY WHETHER THERE IS A NEED FOR SPECIAL LICENSING CRITERIA FOR FACILITIES WHICH PROVIDE CARE UNITS AND OTHER PROGRAMS FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS PATIENTS AND TO REPORT ITS FINDINGS TO THE JOINT LEGISLATIVE COMMITTEE ON AGING.

Be it enacted by the General Assembly of the State of South Carolina:

Licensing criteria to be studied

SECTION 1. The Department of Health and Environmental Control shall study whether there is a need for specific licensing criteria for facilities which provide care units for alzheimer's patients and other specialized programs for individuals with alzheimer's and other related disorders. In conducting this study the department shall consult with the Alzheimer's Disease and Related Disorders Resource Coordination Center, Division on Aging, Office of the Governor and with representatives of homes for the aging and the nursing home industry. The department shall conduct this study using existing personnel to the extent practicable. The department shall submit a report including its findings and recommendations to the Joint Legislative Committee on Aging before January 1, 1996.

Time effective

SECTION 2. This joint resolution takes effect upon approval by the Governor.

In the Senate House March 30, 1995.

Robert L. Peeler,
President of the Senate

David H. Wilkins,
*Speaker of the House of
Representatives*

Approved the 4th day of April, 1995.

David M. Beasley,
Governor

Printer's Date -- April 7, 1995 -- S.

APPENDIX B

**Florida SCU Disclosure Bill
Enacted 1993 Session**

A bill to be entitled an Act relating to Alzheimer's disease; creating ss. 400.175, 400.4177, 400.4785, 400.5571, 400.6045, 400.6255, F.S., requiring nursing homes and related facilities, adult congregate living facilities, home health agencies, adult day care centers, hospices, and adult foster homes that claim special care for persons who have Alzheimer's disease to disclose the reasons for those claims; requiring records of such disclosures to be kept; requiring the Department of Health and Rehabilitative Services to examine the records; providing penalties; providing an effective date.

400.175. Patients with Alzheimer's disease or other related disorders; certain disclosures

A facility licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The facility must give a copy of all such advertisements or a copy of the document to each person who requests information about programs and services for persons with Alzheimer's disease or other related disorders offered by the facility and must maintain a copy of all such advertisements and documents in its records. The agency shall examine all such advertisements and documents in the facility's records as part of the license renewal procedure.

Added by Laws 1993, c. 93-105, § 1, eff. July 1, 1993.

400.4177. Patients with Alzheimer's disease or other related disorders; certain disclosures

A facility licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The facility must give a copy of all such advertisements or a copy of the document to each person who requests information about programs and services for persons with Alzheimer's disease or other related disorders offered by the facility and must maintain a copy of all such advertisements and documents in its records. The agency shall examine all such advertisements and documents in the facility's records as part of the license renewal procedure.

Added by Laws 1993, c. 93-105, § 2, eff. July 1, 1993.

400.4785. Patients with Alzheimer's disease or other related disorders; certain disclosures

An agency licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The agency must give a copy of all such advertisements or a copy of the document to each person who requests information about the agency and must maintain a copy of all such advertisements and documents in its records. The Agency for Health Care Administration shall examine all such advertisements and documents in the agency's records as part of the license renewal procedure.

Added by Laws 1993, c. 93-105, § 3, eff. July 1, 1993.

400.5571. Patients with Alzheimer's disease or other related disorders; certain disclosures

A center licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The center must give a copy of all such advertisements or a copy of the document to each person who requests information about the center and must maintain a copy of all such advertisements and documents in its records. The agency shall examine all such advertisements and documents in the center's records as part of the license renewal procedure.

Added by Laws 1993, c. 93-105, § 4, eff. July 1, 1993.

400.6045. Patients with Alzheimer's disease or other related disorders; certain disclosures

A hospice licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The hospice must give a copy of all such advertisements or a copy of the document to each person who requests information about programs and services for persons with Alzheimer's disease or other related disorders offered by the hospice and must maintain a copy of all such advertisements and documents in its records. The agency shall examine all such advertisements and documents in the hospice's records as part of the license renewal procedure.

Added by Laws 1993, c. 93-105, § 5, eff. July 1, 1993.

400.6255. Patients with Alzheimer's disease or other related disorders; certain disclosures

An adult family-care¹ home licensed under this part which claims that it provides special care for persons who have Alzheimer's disease or other related disorders must disclose in its advertisements or in a separate document those services that distinguish the care as being especially applicable to, or suitable for, such persons. The home must give a copy of all such advertisements or a copy of the document to each person who requests information about programs and services for persons with Alzheimer's disease or other related disorders offered by the home and must maintain a copy of all such advertisements and documents in its records. The department shall examine all such advertisements and documents in the home's records as part of the license renewal procedure.

1993, c. 93-105, § 6, eff. July 1, 1993

Rhode Island

23-17-10.3. Special care unit disclosure by facilities. — (1) On or after January 1, 1994, any nursing facility which offers to provide or provides care for patients or residents with Alzheimer's disease or other dementia by means of an Alzheimer's Special Care Unit shall be required to disclose the form of care or treatment provided, in addition to that care and treatment required by the rules and regulations for the licensing of nursing facilities. That disclosure shall be made to the licensing agency and to any person seeking placement in an Alzheimer's Special Care Unit of a nursing facility. The information disclosed shall explain the additional care provided in each of the following areas:

(a) *Philosophy.* The Alzheimer's special care unit's written statement of its overall philosophy and mission which reflects the needs of residents afflicted with dementia.

(b) *Pre-admission, admission, and discharge.* The process and criteria for placement, transfer or discharge from the unit.

(c) *Assessment, care planning and implementation.* The process used for assessment and establishing the plan of care and its implementation, including the method by which the plan of care evolves and is responsive to changes in condition.

(d) *Staffing patterns and training ratios.* Staff training and continuing education practices.

(e) *Physical environment.* The physical environment and design features appropriate to support the functioning of cognitively impaired adult residents.

(f) *Residents' activities.* The frequency and types of resident activities.

(g) *Family role in care.* The involvement of families and family support programs.

(h) *Program costs.* The cost of care and any additional fees.

The licensing agency shall develop a standard disclosure form and shall review the information provided on the disclosure form by the nursing facility to verify the accuracy of the information reported on it. Any significant changes in the information provided by the nursing facility will be reported to the licensing agency at the time the changes are made.

APPENDIX C

ALZHEIMER'S ASSOCIATION

State Policy Clearinghouse

ALZHEIMER SPECIAL CARE LEGISLATION

MODEL ACT

Title

Section 1. This statute is entitled "The Alzheimer's Special Care Disclosure Act."

Preamble

Section 2. The legislature finds and declares that:

(a) certain nursing home and related facilities, residential care/assisted living facilities, adult congregate living facilities, home health agencies, adult day care centers, hospices, and adult foster homes are presently known to claim special care for persons who have Alzheimer's disease;

(b) it is in the public interest to provide for the protection of consumers regarding the accuracy and authenticity of such claims; and

(c) the provisions of the within Act are intended to require such facilities to disclose the reasons for those claims, require records of such disclosures to be kept, require the appropriate state licensing agency[ies] to examine the records, provide penalties, and provide an effective date.

Definitions

Section 3. For the purposes of this Act, the meaning of the terms specified shall be as follows:

"Alzheimer's Special Care Unit/Program" means any nursing facility, residential care/assisted living facility, adult congregate living facility, home health agency, adult day care center, hospice, or adult foster home that locks, secures, segregates or provides a special program or special unit for residents with a diagnosis of probable Alzheimer's disease or a related disorder, to prevent or limit access by a resident outside the designated or separated area; and that advertises, markets or otherwise promotes the facility as providing specialized Alzheimer/dementia care services.

COMMENTARY

Section 1. *The title of the Act should conform to state practice.*

Section 2. *The preamble establishes the rationale for providing consumer protection in SCUs.*

Section 3. *This section defines Special Care broadly to ensure all possible variations are appropriately covered by the Act. In terms of referring to your state's individual special care options as either "Units" or "Programs" it is best to mirror the language that providers are currently using when marketing them.*

Special Care Unit Disclosure by Facilities

Section 4. Any facility which offers to provide or provides care for persons with Alzheimer's disease by means of an Alzheimer's Special Care Unit/Program shall be required to disclose the form of care or treatment provided that distinguish it as being especially applicable to, or suitable for, such persons. The disclosure shall be made to the state licensing agency[ies] and to any person seeking placement within an Alzheimer's Special Care Unit/Program. The agency shall examine all such disclosures in the agency's records as part of the facility's license renewal procedure, and verify their accuracy.

The information disclosed shall explain the additional care provided in each of the following areas:

(a) **Philosophy:** The Alzheimer's Special Care Unit/Program's written statement of its overall philosophy and mission which reflects the needs of residents afflicted with dementia.

(b) **Pre-Admission, Admission and Discharge:** The process and criteria for placement in, transfer or discharge from the Unit/Program.

(c) **Assessment, Care Planning and Implementation:** The process used for assessment and establishment of the plan of care and its implementation, including the method by which the plan of care evolves and is responsive to changes in condition.

(d) **Staffing Patterns and Training Ratios:** Staff training and continuing education practices.

(e) **Physical Environment:** The physical environment and design features appropriate to support the functioning of cognitively impaired adult residents.

(f) **Residents' Activities:** The frequency and types of resident activities.

(g) **Family Role in Care:** The involvement of families and the availability of family support programs.

(h) **Program Costs:** The costs of care and any additional fees.

Effective Date

Section 5. This Act shall take effect upon passage.

Section 4. *This is the heart of the Act. It is intended to protect the consumers of Special Care Unit/Program services from becoming victims of false claims made by care facilities. Detailed in the Act are specific areas of disclosure that closely mirror those outlined by the Alzheimer's Association in its Guidelines for Dignity: Goals of Specialized Alzheimer/Dementia Care in Residential Settings.*

This section gives the Act "teeth" by spelling out the requirement that the appropriate state regulatory/licensing agency be appraised of any claims made by facilities regarding their Special Care Units/Programs, and provides a record-keeping requirement to ensure that such claims will be verified by the agency that renews the facility's license.

Section 5. *This section sets an effective date for the requirements of the Act to begin to take effect.*

APPENDIX D

REPORT OF THE SUBCOMMITTEE ON
SPECIAL CARE UNITS FOR
PERSONS WITH
ALZHEIMER'S DISEASE

November, 1989

Background

The Nebraska Task Force on Alzheimer's Disease and Related Disorders held a series of town hall meetings across the state in October and November of 1988. A combination of Area Agencies on Aging, Alzheimer's Disease Support Groups, senior centers and community hospitals co-sponsored meetings in Kearney, Ogallala, Scottsbluff, Norfolk, Lincoln, Beatrice and Omaha. The meetings were held to gather information on the needs of those with Alzheimer's Disease and related disorders and their caregivers in order to better plan future activities of the Task Force. It has been estimated that in Nebraska there are 13,129 persons over the age of sixty-five with severe dementias. A new study conducted by Harvard Medical School and published by the Journal of the American Medical Association, indicates that the numbers may be much higher. Based on their estimates, there may be approximately 32,000 Nebraskans with Alzheimer's Disease.

One of the topics that created the most discussion was that of special care units within nursing homes for Alzheimer's Disease patients. Most nursing home administrators and family caregivers testified that special care units are needed. Those in favor of integrating Alzheimer's patients with other residents tended to be from small homes with the capacity to provide individual and specialized attention to those who needed it. Two concerns about special care units were raised, however. Administrators wondered about the source of funds to incorporate the extras necessary for a special care unit and to pay the additional staff. Caregivers questioned whether special care units are always special, or simply a section of a nursing home designated as special.

As a result of these discussions, Legislative Resolution 155 was introduced by Senator Don Wesely and passed by the Legislature. The purposes of this resolution are to conduct a study of appropriate standards for special care units for the victims of Alzheimer's Disease and related disorders and to recommend to the Legislature necessary legislation to ensure appropriate regulation of and standards for such units. The Governor's Alzheimer's Disease Task Force formed a special subcommittee to examine these issues and make recommendations.

The subcommittee met four times between August and December of 1989. They performed a literature search, developed recommendations, and drafted proposed legislation. The results of those efforts are provided in the following sections of this report.

Statement of the Problem

Fulfilling the needs of persons with Alzheimer's Disease presents a variety of special challenges to caregivers. In a nursing home, integration of persons who are severely disoriented with those who are alert may result in inadequate care for both.¹ Development of special units provides the opportunity to address the needs of persons with Alzheimer's by designing an appropriate environment and by assuring that staff have adequate time and training.

Another consideration which necessitates the development of standards for special care units is the fact that such units are currently in existence in the state. Subcommittee members were aware of thirteen units in Nebraska. While the services that are provided may be very good, there are no standards against which to monitor their quality. Families are left to their own devices in determining whether a special care unit is providing optimum care for their family member with Alzheimer's Disease.

The College of Nursing of the University of Nebraska Medical Center, with funding from the Golden Eagles of the Nebraska Fraternal Order of Eagles, recently conducted a survey of nursing homes in the state. The focus of the study was to determine what changes in environment, staffing and training have been made by special care units, whether these changes are directed at modifying or better providing for the special problems and needs of Alzheimer's Disease patients, and what outcomes have resulted from these changes? The study examined differences between nursing homes with special care units and those without. It attempted to determine what if any special guidelines or policies are being used in special care units. Results of the study are provided in appendix A of this report.

Review of the Literature

The purpose of special Alzheimer's Units is to provide a safe, protective, low stimulus environment where demented individuals can interact with others who have similar problems; to provide an environment safe and free from hazards that is predictable, secure, and stable; and to adapt the environment to meet the needs of the demented individual with behavioral problems without the use of chemical or physical restraints, whenever possible. The mission of such units should be to enable residents with dementia to "thrive" given their available potential through institutional intervention, developing their competencies

2. Obtain a medical history and a personal history from families and/or caregivers that includes management techniques, likes, dislikes, interests, fears, hobbies, former profession, people in the person's life that he or she might ask for.
3. To design an environment to provide for differing needs of individuals at varying stages of the disease. The facility/unit should be self-contained and specifically designed or adapted to create a safe, supportive environment that minimizes the need for chemical or physical restraints. An indoor communal area should be provided for the residents. A secure outdoor area should also be provided.
4. Create an environment which is personalized, dignified, safe, secure and maximally predictable. Provide a coherent, thematically consistent program of environmental stimulation (e.g. physical structure, cues and program) which promote and predispose toward pro-social and adaptive behavior, thereby reducing emotional and cognitive stress.
5. Provision of activities which are meaningful to the participant, are enjoyable, give satisfaction, allow experiences of success, sustain old roles, and which significantly reduce the number of empty hours the patient experiences. Special programming should be adapted to the needs and abilities of dementia patients and families. Documented activity programs, exercise and therapies should meet the needs and abilities of each individual at every stage of the disease process.
6. A planned approach to patient rights and quality of life and the provision of respect and dignity which takes into consideration the special handicaps of people with dementia. It can be difficult to communicate respect and dignity toward ill and impaired people. However, the institutional environment and techniques of staff approach to patients can be examined for those things which communicate loss of personhood, dignity roles, freedom and identity. Some of these are amenable to change, and the program should be actively involved in efforts to identify and modify them.
7. Development of an individualized care plan that includes (as appropriate) medical, nursing, psychosocial goals, and behavior management plans, with input from multiple disciplines and is discussed with the family and/or caregiver. Quarterly revision of the care plan, and communication of the plan (or appropriate sections) to all staff involved in care, is essential. Quarterly reviews should examine the ongoing need for psychoactive medications.
8. Provision of medical and nursing care (with specialty consultation when needed) that manages, treats and reviews medication use and concurrent illness, to the extent that patients do not suffer from such excess disabilities or delirium as can be reasonably prevented. Psychoactive medications must never be used as a substitute for staff time or training and will be used only after evidence of the failure of behavior management plans. Physical restraints or psychoactive

and improving upon or ameliorating the effect of their dysfunction(s). Such intervention should increase the possibility and likelihood of a match between the person's abilities and the environment's demands so as to produce a state of competence and well being in residents, staff and families.

The following principles should guide the provision of care to Alzheimer's Disease patients.^{3, 4}

1. Maximize the level of safety of clients by supporting all areas of loss in a prosthetic manner, i.e. ramps, stairs, handrails.
2. Provide the patient with unconditional positive regard.
3. Use behaviors indicating anxiety and avoidance to determine limits of levels of activity and stimuli.
4. Teach caregivers to "listen" to the patient and evaluate verbal and nonverbal responses.
5. Modify the environment to support losses and enhance safety.
6. Provide ongoing education, support, care and problem solving for caregivers.

In addition, a special care unit should adopt the following goals:⁵

1. To recognize each resident with dementia as a unique individual with needs, desires, and abilities.
2. To select staff whose skills, creativity, personality, and interpersonal abilities are consistent with the variety of challenges presented by persons with dementing illness.
3. To train staff members on the normal aging process, the dementias, and patient and personal management techniques.

Specific policies of the units must take into account a wide range of factors, including preadmission procedures, social and environmental issues, appropriate care plans, family and patient rights, safety, behavior management, use of medications and restraints, and staff training and maintenance. Recommended objectives are described as follows:^{2, 6, 7, 8, 9}

1. To assure beds designated as Alzheimer's in units or facilities will serve the persons intended. Persons admitted to the unit/facility should have a primary or secondary diagnosis of A.D. or a related disorder based on physical, mental, psychosocial and social testing. There ought to be some evidence that reversible causes of dementia have been ruled out. Evaluation of residents should be a pre-admission requirement, utilizing accepted diagnostic and screening batteries for dementia, and provide for continued re-evaluation to determine accuracy of diagnosis and causes of exacerbation in dementia symptoms (e.g. to rule out medical illnesses, medication changes, functional psychiatric problems, etc.)

medication should not be used as a response to staff or family distress (which are appropriately dealt with by counseling, training, etc.)

9. A planned approach to provision of safety that includes protection for wanderers, protection against injury or falls, and fire safety (people with dementia may not respond to a fire alarm or may wander back into a facility if left alone.) The plan must have weighed the need for freedom, mobility and maintenance of function against the risk of injury. Manage "wandering", agitation, unpredictable behavior and other signs of confusion as responded to cognitive overload or emotional distress, and not as "acting out".
10. Analyze problem behavior of residents from a nonjudgemental perspective, seeking to establish cause-effect connections, especially to see whether inappropriate programmatic and/or staff interaction may have been at fault.
11. Provide staff who are trained, supervised and supported in such a way as to encourage residents autonomy and assure a high quality life for A.D. and related disorders victims. All employees assigned to an A.D. unit should have prior training and orientation beyond basic nursing or nurses aid skills. Such special training should reflect the current thinking about communicating, relating to and supporting patients, clients and their families.

Criteria for staff who are assigned to a special care unit are: Employment as a nursing assistant or care staff member for at least six months; voluntary assignment to the special care unit; successful completion of the designated training course; selection through use of interviews; and personal traits which include proficiency in present duties, willingness to be part of a team, possession of good communication skills, calm and resilient personality, creativity, good interpersonal skills, patience, flexibility, and possession of a sense of humor.

12. Attempt to reduce staff turnover and "burnout" by proper interviewing, orientation, training, ventilation of frustration, communication and optimal opportunities for work re-assignment on a temporary or permanent basis.
13. To establish minimum staffing levels. These should be set by the regulatory body somewhat higher than for regular nursing home care. Distribution of staff should be adjusted to individual needs and stages.
14. Recognize that the family and/or caregiver are also victims of dementia and provide family support which may include referral, education, support groups, and counseling.

Appendix B describes in detail the specific policies and procedures recommended by the literature for special care units. Appendix C lists components described in the literature that comprise a good training program for staff. Appendix D provides physical standards.

Recommendations of the Subcommittee

The subcommittee on special care units agreed on the necessity for mandating standards for special care units. They recommended that the Department of Health prepare regulations within the confines of the existing statutes. The regulations should be based upon this report, Iowa's law regulating special care units, and Standards for Intermediate Care Facilities - Mental Retardation in Nebraska. If a review of these regulations by the attorney General's Office determines that statutory changes are needed, such legislation should be introduced in the legislative session which follows.

The subcommittee also expressed concern that the units be described with a name that encompasses all dementing disorders. If the regulations refer to "Alzheimer's Units", facilities could conceivably utilize names such as "Special Units" or "Dementia Units" and bypass the regulations. The subcommittee recommends use of the name "Special Care Unit for Dementing Disorders or Illnesses".

Because of the importance of adequate (as well as well-trained) staff for these units, the subcommittee devoted time to discussing appropriate staff ratios. Although some of the literature provides specific "staff-to-patient" ratios, the subcommittee felt that staffing ratios must be based on acuity ratings of the patients. Ratings of this type are successfully utilized in psychiatric units.

The subcommittee recognized that reimbursement for patient care is an issue of major importance. Their recommendation was that Medicaid should provide reimbursement which is also based on an acuity rating of the patients and additional standards required. It appears that the Department of Social Services is well on its way to creating this type of system of payments. They recently submitted a Request for Proposal for development of a case-mix reimbursement system for Medicaid. Such a system would tailor reimbursement to the special needs of the persons served, including their medical condition and their activities of daily living. Reimbursement would take into consideration the extra requirements for special care units, such as pre-admission testing, special staff training, environmental alterations, provision of appropriate activities, family support, and need for higher staffing levels. A firm in Washington D.C. was chosen for this project, and the work on it will soon begin. The deadline for completion is July 1, 1990.

The subcommittee expressed concern that stringent standards for special care units could raise rates for private-pay patients beyond their means. The proposed regulations must be written with that concern in mind.

Appendix A

Nebraska Nursing Home Survey Results
University of Nebraska Medical Center College of Nursing
Rosalee C. Yeaworth, R.N., Ph.D.
Barbara Sand, R.N., M.S.N.

Introduction

The University of Nebraska Medical Center College of Nursing was granted \$5,000.00 from the Golden Eagles of the Nebraska Fraternal Order of Eagles to conduct research in the state on Alzheimer's Disease (A.D.). Part of the study was designed to look at nursing homes in Nebraska with and without Special A.D. units to determine answers to the following questions:

1. What changes in environment, staffing, and training have been made by special units?
2. Are these changes directed at modifying or better providing for the special problems and needs of A.D. patients?
3. What outcomes have resulted from these changes?

Questionnaires were developed and mailed to 13 nursing homes in Nebraska which were identified as having units, and 12 of the 13 responded (92%). Similar questionnaires were mailed to the 190 remaining nursing homes in Nebraska, and 103 responded, for a 54% return rate.

Results

Facilities with special units served larger communities (mean=63,000 population) and were larger facilities (mean=126 beds) with more unskilled beds (mean=108). Seventy-five percent had no skilled beds. The location of facilities with units tended to be in the central and eastern portion of the state (42% eastern, 25% southeastern, 17% northeastern), with no units identified in western Nebraska.

If facilities with units limited admission of A.D. residents, the mean limit was 14%; and most units identified other units within 10-30 miles away (67%). Seventy-five percent had specific admission criteria, and 50% reported using specific admission tools to determine appropriateness of placement on the unit. Eighty-two percent of facilities with units described one to three full time activities persons, and they tended to have more staff employed at their facilities.

Average size of A.D. units in Nebraska is 19.5 beds (range 9-60 beds), and mean percentage of occupancy is 97% (range 90-100%). Most units have been in existence for three years, with a range of one to four years and a mean of 2.5 years.

Major findings of special A.D. units in this study are as follows:

1. Ninety-two percent of nursing homes with A.D. units report a decrease in the use of chemical (medication) restraints on their units. The mean reported decrease in usage is 53%.

2. Eighty-three percent of nursing homes with A.D. units report a decrease in the use of physical restraints on their units. The mean reported decrease in usage is 59%.
3. Typical mean staff-to-patient ratios on special units are: Day shift, 1 staff to 7 patients; Evening shift, 1 staff to 8 patients; Night shift, 1 staff to 13 patients.
4. Problem behaviors are reported to have improved in patients since being on the unit. Changes in behavior noted include: behavior more calm, less disruptive; decreased agitation and physical violence (43%); decrease in wandering (21%); less need for chemical/physical restraints (14%).
5. Perceived advantages of special units are: security to wander safely and maintain freedom (53%); increased supervision and staff meeting patients' special needs (17%); quiet, calm environment (17%).
6. Special staff education before working on the units was varied. Twenty-eight percent had staff view VCR tapes regarding A.D.; 17% had orientation via a "buddy system;" 14% were given reading material on A.D.; only 14% had special classes on A.D.; and 7% reported no formal training of staff.
7. Physical environment changes for the unit were reported by all respondents. Most frequently mentioned changes were a large fenced outside area and separate activity/recreation area (92%), separate dining area (75%), soft colors (67%), muted, calm theme (58%); and locked doors (50%).
8. All units responded as having some types of activities available to patients on the day and evening shifts; these include games of varied nature (100%), music programs and sing-alongs (67%), church services and exercises (50%), walking, cooking and household activities (42%). Sixty-seven percent reported having special events and activities that included families.

Nursing homes in Nebraska without special A.D. units reported a range of 0-25% (mean of 8%) of their residents with a diagnosis of A.D., and 0-100% (mean of 13.5%) of these had behavioral problems severe enough to require the use of chemical (medication) restraints. Zero to one-hundred percent (mean of 14%) required the use of physical restraints. Frequency of medication administration for behavioral problems in A.D. patients in these facilities was twice a day (37%) and three times a day (18%). Both facilities with units and without agreed that behavior problems that lead families to institutionalize their loved ones were wandering, combative behaviors, increased memory loss, inability to perform their activities of daily living, and physical decline that requires 24-hour supervision. The most problematic behaviors cited by both facilities were communication problems, memory disturbance, demanding/critical behavior, and physical violence. Interestingly, daytime wandering was identified by facilities without units as the number one problem (15%), whereas wandering was only cited as problematic by facilities with special units with 3% frequency.

Conclusions

The following conclusions can be drawn from the present study conducted in Nebraska long-term care facilities.

1. Special A.D. units tend to be larger communities with more unskilled beds, are located in central to eastern Nebraska, and run extremely high occupancy rates.
2. Nursing homes with special units use less chemical and physical restraints for A.D. patients.
3. Problem behaviors improve in patients with A.D. when they are placed in special A.D. units.
4. There are many advantages of A.D. units, the most prominent being security to wander safely which reduces the need for chemical and physical restraints. This provides more personal sense of freedom and dignity.
5. Special staff education/training is lacking for personnel working on A.D. units.
6. Physical and environmental changes were made by all facilities with units in Nebraska, and activities are available to patients.
7. Daytime wandering is a priority problem in facilities without units and is not seen as a problem in facilities with special units.

Appendix B

POLICIES AND PROCEDURES FOR
SPECIAL CARE UNITS

PROGRAM OF CARE: A program of care shall be submitted to the department for approval 90 days before a special care unit is opened in a long-term care facility. A new program of care shall be submitted before programs are substantially changed. The program of care shall include:

- a. A statement describing the population to be served
- b. A copy of the statement of philosophy and objectives
- c. Copy of admission and discharge criteria
- d. Copy of the floor plan
- e. List of titles of policies and procedures developed for the unit
- f. Copy of the proposed staffing pattern
- g. Plan for staff training
- h. Copy of visitor, volunteer policies, and safety policies
- i. Description of the following:
 - (1) Activities program
 - (2) Therapeutic programs
 - (3) Social Services program
 - (4) Family programs

PHILOSOPHY: A statement of philosophy shall be developed for each special care unit which shall state the beliefs upon which decisions will be made regarding the unit.

OBJECTIVES: A statement of objectives for each special care unit shall be developed for the unit as a whole. Each of the objective statements shall be stated in terms of expected results.

POLICIES AND PROCEDURES: The policies and procedures for the facility as a whole shall be followed except as defined in separate written policies and procedures which shall be implemented in each special care unit.

- a. Admission and discharge policies and procedures which state the criteria and the evaluation process which is to be used.
- b. Safety policies and procedures which state the actions to be taken by staff in the event of a fire, natural disaster, emergency medical or psychiatric event, when a resident is discovered to be missing from the unit, and when hazardous cleaning materials or potentially dangerous mechanical equipment are being used on the unit. This use is not recommended, but procedures are needed if such use is absolutely necessary.
- c. Policies and procedures which state the unique programs and services which are offered in the special care unit including rationale for each.
- d. Staffing policies and procedures which state minimum numbers, types and qualifications of staff on the unit.

- e. Visiting policies which suggest times for visiting and how the rights of the resident to free access to visitors shall be assured.
- f. Family programs, policies and procedures which describe services for families which help them to understand and react appropriately to the condition and behavior of the resident.
- g. Quality assurance policies and procedures which list the process and criteria to be used in monitoring of drug use, restraint use, infections, incidents and acute behavioral events. (These would include policies and procedures on the development of client plans of care and quarterly review by a multidisciplinary team of individuals).

PRE-ADMISSION ASSESSMENT: A pre-admission assessment of physical, mental, social and behavioral status shall be completed to determine if the applicant meets the admission criteria.

- a. Become part of the permanent record upon admission of the resident.
- b. Be completed by a registered nurse and a staff social worker or social work consultant.
- c. Include patient's daily routines, habits, occupation, "typical day" etc. To be used for planning care and activities.

STAFF TRAINING: All staff must be able to read and understand English. All staff working in a specialized unit shall have training appropriate to the needs of the population being served.

- a. Prior to working on the unit, personnel should receive initial training of a minimum of eight hours on the needs of the resident being served and management techniques for behavioral problems. Personnel shall be reviewed every 6 months for rapport and compatibility with the clients of the unit.
- b. Licensed nurses, certified aides, certified medication aides, social services, housekeeping, and activity personnel shall have a minimum of four hours annually of department approved training related to the needs of the residents being served.

STAFFING PATTERN: The staffing of the special care unit shall be based on acuity ratings of the patients. The staff on this unit shall be counted separately. It is recommended that one full time activity person be assigned to the unit per 20 residents.

LICENSURE: A facility may request licensure as an intermediate care unit or a skilled nursing facility with a unit. The license shall state the population to be served and the number of beds in the unit. The optimum number of beds is fourteen to twenty.

- a. Application for this category of health care shall be submitted on a form provided by the Department of Health.
- b. Plans to modify the physical environment shall be submitted to the Department of Health for review and approval/disapproval.

Appendix C

Training Program For Staff:

Goals: Educate personnel on **effective** approaches and techniques in working with clients on unit.

Training designed to: Enable staff to help residents in ways that would bring about a reduction in incontinence, night wandering, and combativeness and would improve the appearance and responsiveness of residents.

1. Change many negative attitudes of staff toward persons with dementia.
2. Expand staff's repertoire of approaches.
3. Increase staff skills in helping residents to continue to function maximally.
4. Develop a cohesive staff team. ¹

Training Content:

Initially content should include the following:

1. Dementias -- reversible vs. irreversible
2. Alzheimer's Disease -- pathophysiology, theories of causation diagnosis, etc.
3. Stages/progression
4. Characteristic behavioral problems
5. Management of problematic behaviors
6. Excessive disabilities
7. Special Care Units -- goals, philosophy, purpose, benefits, structured environment and routines
8. Long term caring
9. Activities
10. Support for families and staff

Content should be covered in an 8 to 10 hour period (minimum) initially. Suggest two 4-5 hour sessions.

Suggest monthly inservices and weekly staff meetings.

Other content to be included in inservices/staff meetings:

- Communication skills, body language
- Stress management
- Staff interaction
- Creative problem solving
- Death and dying
- Dealing with families
- Activities

Suggest consultation from appropriate personnel to unit at least twice a year (quarterly ideal) to discuss problems with staff, review care plans, suggest improvements in care, problem solve, trouble shoot, etc.

Appendix D

PHYSICAL STANDARDS FOR SPECIAL CARE UNITS ^{3,4}

- A. Residents and/or staff from other units within the nursing home shall not pass through the special care unit in order to reach exits or other areas of the nursing home.
- B. If the special care unit is to be a locked unit, all locking devices shall meet the Life Safety Code, and any requirements of the State Fire Marshall. If the special care unit is to be an unlocked unit, a system of security monitoring will be required. The facility shall identify its method for security of the unit and monitor the effectiveness of the security system.
- C. The outdoor activity area, shall be secure for the special care unit. Non-toxic plants shall be used in the secured outdoor activity area. Chairs should be provided for the outside area and there should be no benches without backs.
- D. Within the special care unit, and in the outdoor activity area, there shall be no floor level or grade change (no steps or slopes).
- E. Dining and activity areas for the special care unit, shall be located within the special care unit, and shall not be used by other nursing home residents.
- F. In addition to the required space for dining and activity areas, the facility shall provide (excluding hallways) at least five square feet per resident for activity space and at least five square feet per resident for dining space, or at least ten square feet per resident if the dining and activity areas are combined.
- G. A private area shall be provided to allow nursing staff to prepare daily patient reports and should be in view of the unit (i.e. nurses' station).
- H. If a non-ambulatory resident is admitted, resident toilets shall be large enough to accommodate that person and two staff members.
- I. If the lounge/activity areas are not adjacent to the resident rooms, there shall be one uni-sex resident toilet for each ten residents in clear view of the lounge/activity area for easy access.
- J. Special consideration should be given to the design of lighting intensity at the resident beds.

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APPENDIX E



**NATIONAL INSTITUTE ON AGING
COLLABORATIVE STUDIES**

**SPECIAL CARE UNITS
FOR
ALZHEIMER'S DISEASE**

DESCRIPTION OF THE PROJECTS

Prepared by the Coordinating Center
at
The Research Division
Hebrew Home for the Aged at Riverdale
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September, 1993

NATIONAL INSTITUTE ON AGING COLLABORATIVE STUDIES: SPECIAL CARE UNITS FOR ALZHEIMER'S DISEASE

The National Institute on Aging Special Care Unit (SCU) Initiative was established in 1991 to undertake the systematic study of the nature and outcomes of special care units for persons with Alzheimer's disease (AD) or related dementias. Under this initiative, NIA has funded ten research projects to study SCUs throughout the United States. While each of the ten studies has a unique methodological focus, the investigators collaborate on issues such as standardizing a definition of SCUs; assessing residents with dementia; and evaluating the outcomes of care on residents, staff, and family caregivers. Nursing homes from around the country are being randomly selected to participate in this study. Within selected facilities, residents and their caregivers are invited to participate. The ultimate goal of the NIA SCU Initiative is to determine the effectiveness and outcomes of these units in order to improve the quality of care provided to persons with dementia and their families and to assist public policymakers in making informed decisions.

It is estimated that some 4 million American adults are afflicted with Alzheimer's disease or similar disorders and that at least 50 percent of nursing home residents suffer from some type of dementia, primarily AD. As the population ages, this number may increase dramatically, to more than 14 million by the year 2040. Because AD follows a course of progressive deterioration that often lasts 10 to 15 years, the burden of care is extremely heavy and increases as the afflicted person moves through the several stages of the disease, almost inevitably requiring nursing home care. Recent estimates indicate that dementia costs the American economy nearly \$90 billion, with a large percentage of the cost of care associated with formal care provided in a nursing home.

In recent years, the growth of SCUs has been explosive. According to a 1991 national survey by The George Washington University, of the 15,490 nursing facilities in the United States with over 30 beds, 1,463 had special units or programs for persons with dementia and 1,318 had separate units. Despite the growing interest in SCUs, there has been little research on the special care approach. We need to know about how SCUs work, what defines them, or whether they make a difference for people with AD and their caregivers. Institutional care of persons with AD presents unique problems, including how to design the most appropriate model of care for such persons, including staffing, training, programming and environment. Another issue concerns whether residents with dementia should be integrated, or "mainstreamed", with residents who are not cognitively impaired, or segregated in a unit designed and operated specifically for them, called "special care units". In addition, the growth of SCUs has initiated a number of public policy debates over such issues as regulations, guidelines, and reimbursement.

The National Institute on Aging Special Care Units Initiative is the first multi-center national study to examine SCUs and their impacts on residents and others. The NIA is the lead Federal agency for Alzheimer's disease research, including studies of the basic, clinical, epidemiological, and social aspects of this and other related dementia's of aging. The SCU initiative is part of a wider research effort examining the social and health care needs of people with AD. The NIA SCU Initiative has been endorsed by organizations representing nursing home providers and administrators, including the American Association of Homes for the Aging (AAHA) and the American Health Care Association (AHCA), as well as consumer organizations, including the Alzheimer's Association.

Special Care Units for Alzheimer's Disease

Ten collaborative studies were funded beginning in 1991 to examine the nature of Special Care Units for dementia and to evaluate their impact on nursing home residents, family members, and nursing home staff. These ten studies share a common database for describing SCUs and their impacts. Two associated studies are closely linked with this collaborative effort.

PI: Denis A. Evans -- Rush-Presbyterian-St Luke's Medical Center
Longitudinal Study of Four Types of Alzheimer's Disease
Special Care Units

This longitudinal study is comparing care for persons with Alzheimer's disease in four settings: (1) usual inpatient nursing home units, (2) Alzheimer's disease inpatient nursing home units, (3) usual adult day care units, and (4) an Alzheimer's disease day care unit. Data are collected on physical function, cognitive function, behavioral problems, use of physical restraints, medication use, and falls, injuries, and hospitalization at regular intervals over a 36-month period.

PI: Leslie A. Grant -- Univ. of Minnesota, School of Public Health
Special Care Units in Minnesota Nursing Homes

This study describes and classifies care arrangements in nursing homes for persons with dementia, examines outcomes associated with the care arrangement types, and tests the effectiveness of a biography-construction exercise performed by family members shortly after the admission of a relative in nursing homes throughout Minnesota. A variety of outcome measures are obtained for residents with dementia, cognitively intact residents, family members, and nursing home staff.

PI: Douglas Holmes -- The Hebrew Home for the Aged at Riverdale
Differential Costs and Inputs for Special Care Units

The goal of this study is to determine whether there are differential service inputs associated with SCU care in comparison with non-SCU care, and with different subgroups among demented residents in 12 nursing homes. Data are collected on the service provider, the service recipient, and the nature, date, and time of the service. Cost effect and cost benefit modelling are used to address policy concerns related to calculating case mix based reimbursement rates.

PI: Nancy G. Kutner -- Emory University
Budd Terrace SCU Care Model: Multidimensional Analysis

This is a study of a single Special Care Unit located in an intermediate care facility. Ethnographic observation of resident and staff behavior are analyzed. Of particular interest is the circadian behavior changes in AD patients referred to as sundowning--the onset or exacerbation of agitation, restlessness, panic, intensified disorientation, and verbal or physical outburst in the afternoon or evening. Sundowning represents a significant management problem, and the control of behavioral outburst require labor-intensive and emotionally taxing attention from families or other care providers. Outcome measures include resident behavioral disturbances; family satisfaction, involvement and morale; and staff job satisfaction, involvement and support.

**PI: M. Powell Lawton -- Philadelphia Geriatric Center
A Stimulation Retreat Program for Alzheimer's Patients**

The purpose of this project is to examine the effect of individually tailored intervention which prescribes more stimulation or less stimulation according to the patient's needs in two identical 50 bed Special Care Units. The impact of the intervention is assessed by means of direct testing of residents, rating by staff members and family members, and the direct observation of behavior. Resident outcome measures include cognitive functioning, health nutritional status, ADLs, psychopathology, behavior, participation in activities, socialization, and affective status. Family outcomes include well-being, attitude, and number of visits.

**PI: Joel Leon -- George Washington University Medical Center
National Evaluation of Special Care Units Project**

This project examines outcomes for a nationwide sample of dementia patients recently admitted to Special Care Units and to standard nursing homes. Standardized samples of 600 persons with AD entering each type of care setting are evaluated at time of placement and six months later. A significant family member for each resident also provides information. Outcome measures for residents are length of survival, health status, hospitalizations, catastrophic reactions, agitation, cognitive functioning, falls and injuries, physical restraints and psychotropic drugs used, incident reports in the medical record, and level of participation of family activities. Outcome measures for families include satisfaction with care, caregiver stress, involvement in terms of visits and care planning.

PI: David A. Lindeman -- East Bay Institute for Research and Education
Alzheimer's Special Care Units - Longitudinal Outcome Study

This longitudinal study measures the outcomes and effectiveness of Alzheimer's disease Special Care Units for residents, family caregivers, and staff. Data are collected on 172 persons with AD in SCUs and 172 persons with AD in non-SCU nursing homes in California 5 times over two years. Questionnaires to nursing home staff members and family caregivers, direct observation of residents and nursing homes, and review of medical charts are the primary means of data collection. Analyses relate demographic information, nursing home characteristics, problem behaviors, physical and pharmacological restraints, health, functional and cognitive status, caregiver stress and satisfaction, staff stress and satisfaction, and activity programming.

PI: Rhonda J. V. Montgomery -- University of Kansas
Special Care Units: Impact on AD Residents, Family, Staff

The goal of this study is to construct measures to reliably assess various elements of Special Care Units and programs for residents with Alzheimer's disease and to investigate the impact of each element on residents, family, and staff. The five elements of SCUs to be studied are staffing, training, environment, policies, and program. Data are being collected from 900 nursing home residents residing in 100 nursing homes (50 with SCU, 50 without, but matched on other characteristics) in North Carolina (24), Michigan (42), and Washington (44). Data are also obtained from key administrators, staff, resident charts and records, and through questionnaires to family members and staff who provide direct care to residents in a longitudinal design over an 18-month period. Outcome measures include resident physical functioning, social behavior, problem behavior, mobility, time use and use of restraints; family involvement with the nursing home and satisfaction with care; and staff turnover, attendance patterns, job satisfaction, and morale.

PI: John N. Morris -- Hebrew Rehabilitation Center for Aged,
 Boston, MA
**Evaluating a Family Partnership Program in Special Care
 Units**

This study evaluates a formal Family Partnership Program between families and staff in Special Care Units in comparisons of 234 residents in each one of a matched pair of nursing homes with SCUs in Massachusetts, Rhode Island, and New Hampshire. The program is randomly assigned to one of the pair of nursing homes. The Family Partnership Program is comprised of six modules: Resident Assessment and Care Planning; Family Resource Center/Network; Family Caregiving; Enriched Visitation, Involvement in Activities Programming; and Special Care Community Caregiving. Outcome measures for residents include changes in cognitive status, mood, involvement, social response patterns, physical functioning, and health. Family members outcome measure include satisfaction with care, level and nature of involvement, and morbidity.

PI: Philip D. Sloane -- University of North Carolina
Outcomes of Alzheimer's Special Care Units in Four States

This study examines outcomes of nursing home care among persons with Alzheimer's disease and related disorders in all nursing homes and Special Care Units in Kansas, Maine, Mississippi, and South Dakota. (The study states are participating in Health Care Financing Agency's (HCFA) Multi-State Nursing Home Case Mix and Quality Demonstration Project, a 5-year longitudinal study of all nursing home residents in those states which is collecting standardized data on all residents every year.) Both demented and non-demented patients are evaluated on physiologic function, self care, affect and well-being, behaviors, and freedom from restraints. SCU characteristics associated with better resident outcomes are identified in terms of administrative characteristics and policies, staff characteristics and behaviors, and physical characteristics of the SCUs.

Associated SCU Research Studies

PI: Jeanne A. Teresi -- Hebrew Home for the Aged at Riverdale
Impact of Special Care Units in Nursing Homes

This is a 12-month longitudinal study of SCU impact on cognitively impaired residents and non-cognitively impaired residents living in residential health care facilities in five Northeastern States. SCU program attributes are delineated and defined and subsequent analyses focus on the relationship between each attribute and patient outcomes. 960 patients (320 non-cognitively impaired, 320 cognitively-impaired non-SCU, and 320 SCU) are selected from among new admissions at 32 sites. Outcome measures include a number of standardized measures of mental status, ADL, depression, behavior patterns and morale, collected at two points in time during site visits. Information is collected through chart reviews with key informants (usually nurses) and patient interviews. Multivariate analyses are used to identify direct and indirect relationships among the data.

PI: Sheryl I. Zimmerman -- University of Maryland
Aged with Dementia: Facility Effects on Health Outcomes

This study describes and compares the characteristics of a diverse set of 59 nursing homes which contain a mix of patients similar to those in U.S. nursing homes generally. Analyses assess the relationship between nursing home characteristics (such as staff/resident ratio and resident involvement in activities) and health outcomes including morbidity, health care use, and mortality for residents with AD during the year following admission to the nursing home. The project also examines whether nursing home characteristics influence functional outcomes such as cognition, independence in activities of daily living, and behavior for survivors one year after admission, and whether the nursing home characteristics which are beneficial for demented residents also benefit non-demented residents. The study includes 6 special care units for persons with AD.

The Financial Cost of Alzheimer's Disease

PI: David A. Lindeman -- University of California Davis
Costs of AD Special Care Units

This study of the costs of Special Care Units for Alzheimer's disease includes data on the nature and duration of services rendered to individuals as part of the development of a patient-specific cost-of-services measure. The goal of the project is to quantify the costs of care among SCU demented, non-SCU demented, and non-demented residents in 25 Special Care Units and 15 skilled nursing facilities in California. Other goals are to identify subgroups with different levels of service needs, to compare the cost-effectiveness of SCU vs. non-SCU care for demented patients, and to use a cost-benefit approach to evaluating the extra inputs assumed to be associated with the SCU approach.

PI: Dorothy P. Rice -- University of California, San Francisco
Cost of Formal and Informal Care of Alzheimer's Patients

The goal of this study is to estimate the current direct and indirect costs of Alzheimer's disease, based on longitudinal data on the utilization and costs of medical, social, and informal services for institutionalized and non-institutionalized persons with AD. Data were collected in California from approximately 100 non-institutionalized persons with AD and their caregivers, and 100 institutionalized persons and their caregivers. Information is based on formal medical and health care expenditures such as physician services, laboratory tests and other diagnostic procedures, drugs and prescriptions, home health care, other medical personnel, hospital and nursing home care; formal social service expenditures such as senior center services, adult day care, nutrition programs, transportation services; informal care provided by family members and caregivers such as assistance with household chores, mobility and basic activities of daily living; and societal costs such as productivity losses of both victims and caregivers. The costs to the nation of AD will be estimated using the data collected in California.

APPENDIX F

Evaluating the Physical and Caregiving Environment of Alzheimer's Disease Special Care Units

Selected Indicators of Environmental Quality in Alzheimer's Disease SCUs

from the Therapeutic Environment Screening Scale (TESS-2+
and the Resident and Staff Observation Checklist (RSOC)

Philip D. Sloane, MD, MPH
Professor of Family Medicine and Epidemiology,
University of North Carolina at Chapel Hill

Note: Measures of quality of care in
Special Care Units are not well developed. These
measures are unproven but are based on
the existing literature and ongoing studies.
Both the TESS and the RSOC are undergoing continued
development and validation.

December, 1993

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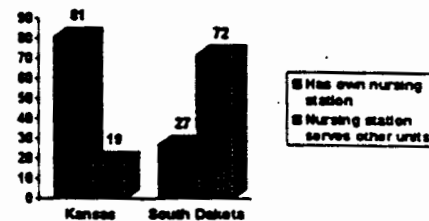
December, 1993

Relationship of Unit to Nursing Station

Rationale: In general, units which have their own nursing station may be more self-contained, reducing confusing traffic to and from the unit. In addition, having staff do their work on the unit means that they are likely to be present more consistently on the unit. However, many authorities consider the traditional fortress-like nursing station to not be conducive to good dementia care. Instead, they prefer to see a station on the unit which is relatively small and unobtrusive.

Does the Unit Have Its Own Nursing Station?

- Arrangements Among the SCUs in 2 States -



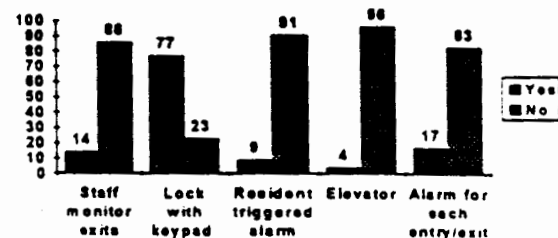
Methods of Controlling Unauthorized Exiting

Rationale: resident safety and autonomy, and staff efficiency may be compromised if wanderers cannot safely explore the unit

Caution: exit controls may be obtrusive or noisy; resident freedom can be limited, especially if the unit does not address needs

How Nursing Home SCUs Monitor Their Exits

- percent of units using selected techniques -

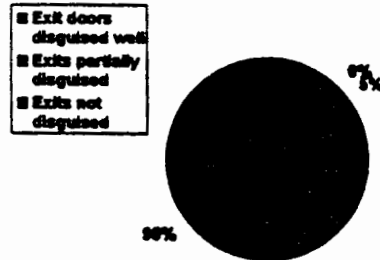


Disguising Exits

Rationale: Some residents will become disturbed if they recognize exits and are unable to get out; disguised doors can help prevent this

Do SCUs Disguise Exits?

- Percent of SCUs Observed (N=76) -

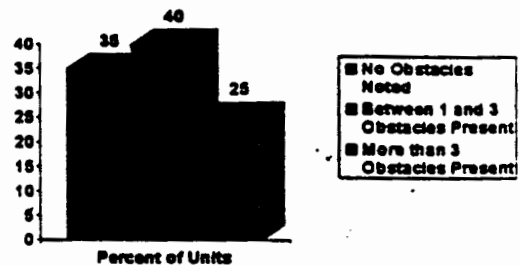


Obstacles in the Hallway

Rationale: Obstacles in hallways, such as linen carts, chairs along railings, and mop buckets can constitute hazards for wandering residents

Obstacles in the Hallway

- Results of Observations in 75 SCUs -



Homelike Quality of Public Areas

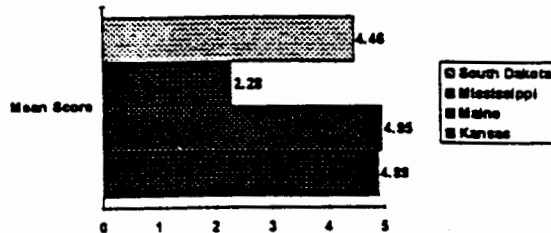
Rationale: A homelike environment in dining and activity areas can enhance resident mood and reduce confusion

Elements of the Homelike Scale for Assessing Public Areas

	Desirable (=1)	Undesirable (=0)
Size	small	large
Lighting	lamps/incandescent	fluorescent/ceiling
Flooring	carpet/rug	hard surface
Accessories	present	absent
Walls	pattern/paper	flat paint
Furniture:		
variation	present	absent
arrangement	social clusters	rows
visual pattern	present	absent
finish/surface	wood/fabric	metal/vinyl/plastic
Window treatment	curtains	blinds

Average Score on the Homelike Scale of Public Areas in Nursing Home SCUs in 4 States

(Possible range: 0 = institutional to 10 = homelike)

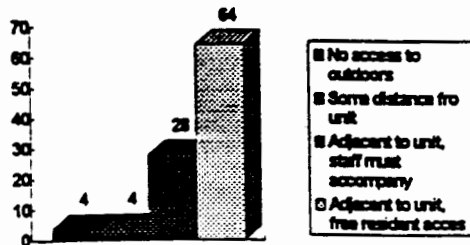


Outdoor Courtyards in SCUs

Rationale: Outdoor space provides exercise, fresh air, and sunshine. Health and mood will be enhanced by ready access to outdoors. Ideally, residents of SCUs should have immediate access to outdoor spaces which are safe, pleasant, and landscaped to provide stimulation and to accommodate activities.

Enclosed Outdoor Spaces in 76 SCUs in 5 States

- As Percent of Units Visited -

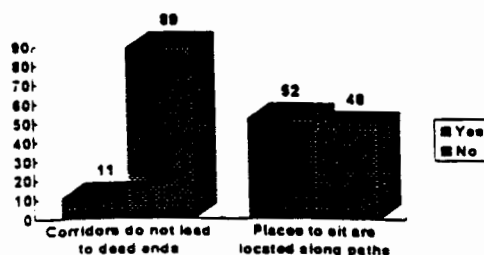


Walking and Wandering Pathways in SCUs

Rationale: Ambulatory residents with dementia should be able to walk from one interesting place to another. Therefore, hallways should be designed so as not to have dead ends. In addition, having places to sit along or adjacent to the corridor (for example, in alcoves) may enhance resident interest and reduce agitated wandering.

Characteristics of Hallways and Indoor Walking Paths in 75 SCUs

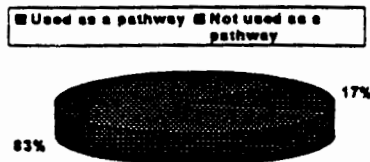
- Percent of SCUs Visited -



Use of an SCU as a Pathway from One Part of a Facility to Another

Rationale: Minimizing the level of distracting stimuli is a goal of most SCUs. For this reason, units that have a stream of traffic going through them may have increased levels of resident agitation. Therefore, it is ideal for a unit to not be used as a pathway from one part of a facility to another.

How Often SCUs Are Used as Pathways from One Part of a Facility to Another - Percent of SCUs -

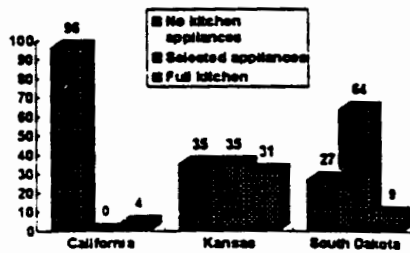


Kitchen Appliance Availability on Special Care Units

Rationale: The availability of kitchens for resident and staff use on Alzheimer's disease Special Care Units has several potential advantages:

1. Snacks can be served at any time and can be kept in the refrigerator.
2. Activities that involve food, such as baking, can occur.
3. Families can bring in food and warm it up, or refrigerate it, making the unit feel more like home to them.

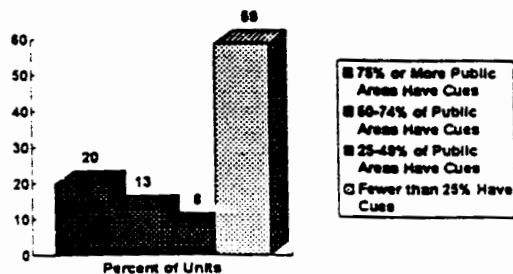
Availability of Kitchen Appliances in SCUs in 3 States - As Percent of Units -



Directional Cues in Public Areas

Rationale: People with dementia usually do not remember where things are. Therefore, when they walk out of their rooms it helps for them to be able to see something that leads them toward an activity area. This can be a sign, a direct line of sight to the area, or some other visual cue (such as an awning).

Directional Cues in Public Areas in 76 SCUs

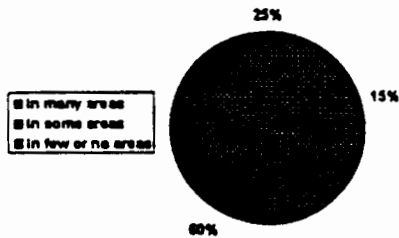


Glare in Special Care Units

Rationale: The aging eye cannot accommodate changes from bright light to shadow nearly as well as that of younger persons. Furthermore, changes in the lens of the eye make older adults more bothered by glare. This is important in the design of all environments for older adults. In Alzheimer's disease, however, reduction of glare is particularly important, since inappropriate visual stimulation can lead to confusion and agitation.

Presence of Glare on Special Care Units

- Results of Daytime Observations in 73 SCUs -

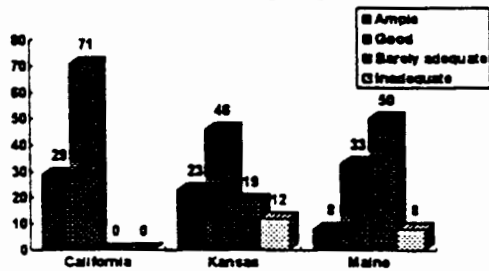


Light Level in Hallways and Activity Areas

Rationale: Hallway light should be adequate and even, so that ambulatory SCU residents are able to move about safely and to avoid obstacles. Similarly, lighting in activity areas should be bright and even.

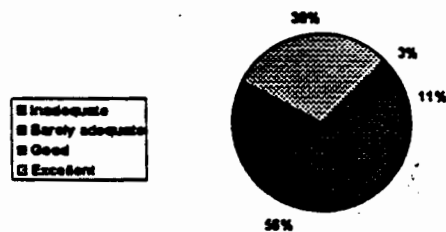
Hallway Lighting in SCUs in 3 States

- Percent of SCUs with Various Lighting Characteristics -



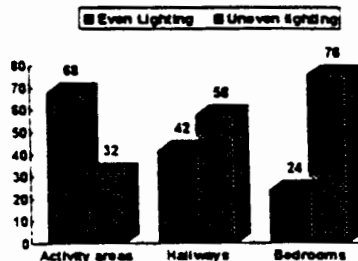
Light Levels in Activity Rooms in 76 SCUs

- Percent of Units -



Evenness of Light in 76 SCUs

- Percent of Units -



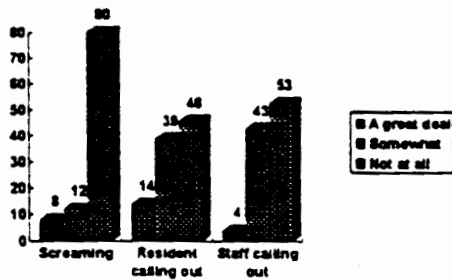
Potentially Noxious Noises on Special Care Units

Rationale: Persons with Alzheimer's disease have difficulty "tuning out" environmental noises. Thus, potentially noxious or confusing noises can lead to agitation and should be carefully controlled on SCUs.

There are 2 categories of such noises: human noises (screaming and calling out) and mechanical noises (electronic equipment, alarms, intercoms, and unit machinery)

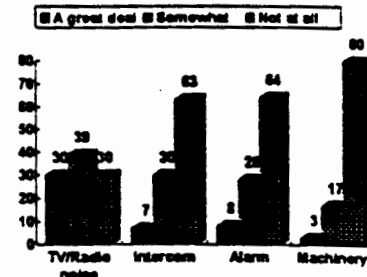
Presence of Human Noise on 76 SCUs

- Percent of SCUs With Problem Noises During Visit -



Presence of Mechanical Noise on 76 SCUs

- Percent of SCUs With Problem Noises During Visit -



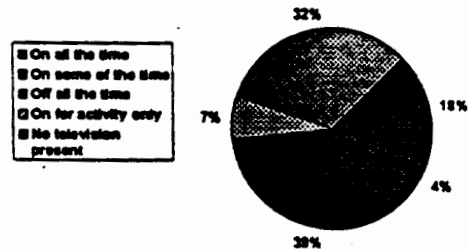
Television in Public Areas

Rationale: Television should generally be off or absent from public areas. Residents with Alzheimer's disease cannot follow most programming and find TV confusing. The extra noise may increase resident agitation. Furthermore, staff often watch the television programs and are less available to care for the residents.

Television can, however, be beneficial when selected programs (such as videotapes of old movies) are used as planned activities.

Use of Television In 76 SCUs

- Percent of Units With Various Television Arrangements in the Main Public Area -



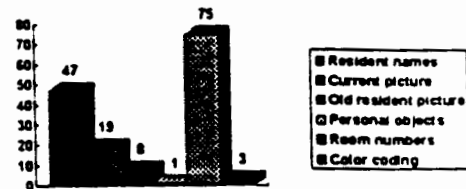
Use of Visual Cues to Identify and Personalize Resident Rooms

Rationale: Persons with Alzheimer's disease and related disorders often cannot remember where their room is located. They may be helped to find their rooms by having something at the entrance to the doorway that has significance to them. Such visual cues can include pictures, names, objects, or colors.

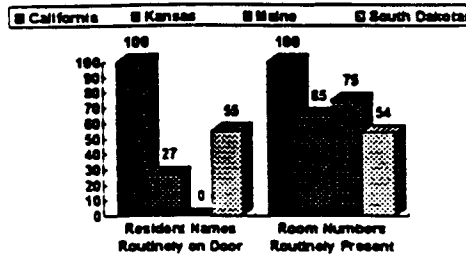
Unfortunately, no single type of cue works for more than a small minority of Alzheimer's residents, and many do not seem to recognize any cues. Some cues, such as colors, require abstract reasoning ability. Since abstract reasoning is lost early in the disease, such cues are generally ineffective.

Use of Visual Cues to Identify Resident Rooms

- Findings From 76 SCUs in 5 States, as Percent of Units that Routinely Used Various Methods -



State Variation in the Use of Visual Cues to Identify Resident Rooms - Percent of SCUs -

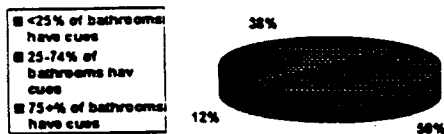


Use of Visual Cues to Identify the Bathroom

Rationale: Persons with dementia often have little warning when they need to relieve themselves. When the urge comes, they often have just a few seconds to look around, locate the bathroom, and get to the commode. For this reason, visual cues that identify where the bathroom is located will help maintain continence in some SCU residents.

How Often Bathrooms in Resident Rooms Have Cues to Help Residents Locate Them (e.g., an open door with the commode visible from the bed, or a sign on a closed door)

- as percentage of SCUs evaluated (n=76) -

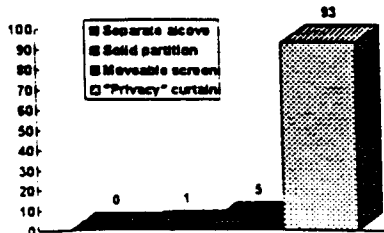


Provision of Privacy in Shared Rooms

Rationale: Insufficient privacy is one of the most common complaint of nondemented residents of nursing homes. Among persons with dementia, adequate privacy may reduce agitation, prevent altercations, and make it easier for families to visit. Since the majority of SCU residents are in shared rooms, facilities that pay special attention to privacy in such rooms may have improved resident satisfaction and reduced agitation.

Provision of Privacy in Shared Rooms: Observations in 76 SCUs in 5 states

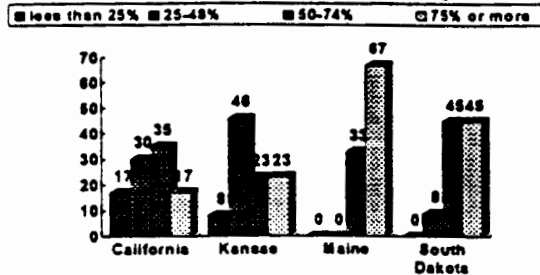
- Percentage of Homes With Various Provisions for Privacy -



Personal Pictures and Mementos in Resident Rooms

Rationale: Having objects and pictures of personal significance in his or her room provides a valuable link to the resident's personal identity and lifetime memories. Such objects help make the room seem more like home, thus reducing confusion and agitation. They may also provide pleasure when used for reminiscence.

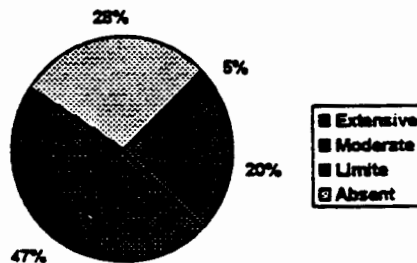
Percent of SCU Residents That Have At Least 3 Personal Pictures or Mementos in Their Rooms, By State



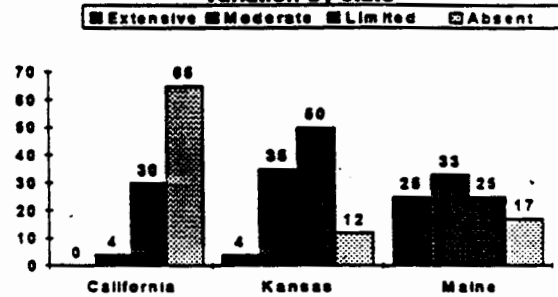
Tactile Stimulation Opportunities in SCUs

Rationale: Residents of SCUs are more likely to engage in meaningful behavior if objects are readily available in the environment for them to touch, manipulate, pick up, carry, fold, taste, smell, and give to others. The extent to which such tactile stimulation opportunities are present in public areas may be a measure of the quality of programming in an SCU.

Tactile Stimulation Opportunities in 76 SCUs



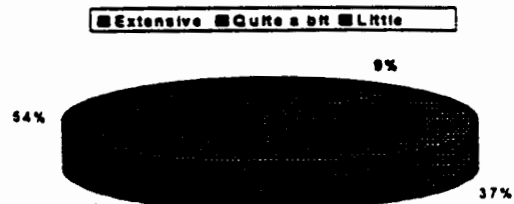
Tactile Stimulation Opportunities in SCUs: Variation by state



Resident Appearance

Rationale: One observational measure of the quality of care on an SCU is the extent to which the appearance of residents in public areas reflects attention to individual identity and pride. Indicators of this measure include hair styling, individual-appearing street clothes, and extras such as jewelry, watches, and belts.

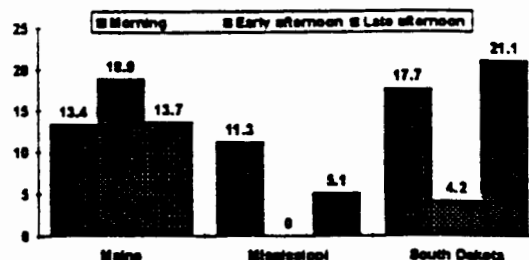
Resident Grooming in 76 SCUs: Attention to Individual Identity and Pride - Percent of SCUs by Rating -



Involvement of SCU Residents in Planned Activities

Rationale: Persons with Alzheimer's disease and related dementias demonstrate little initiative to engage in purposeful activities on their own. As a result, they particularly benefit from appropriate structured activities. For this reason, the "better" Special Care Units tend to offer individual and group activities throughout the day. Thus, rates of participation of residents in structured activities may constitute a measure of quality of care in SCUs.

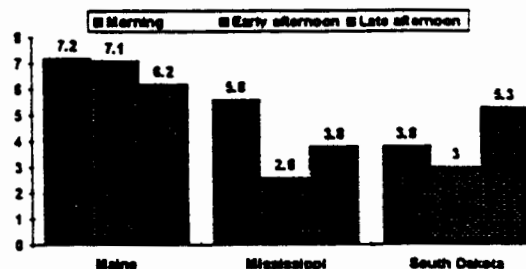
Percent of SCU Residents Involved in Structured Activities: Variation by State and Time of Day



Percent of SCU Residents Receiving One-On-One Care

Rationale: Provision of one-on-one care is an important aspect of nursing home services for persons with moderate and advanced dementia. The extent to which staff are involved in direct care, as opposed to group activities, depends to a great extent on the severity of resident impairment in a unit. Thus, the amount of individual attention, though an important indicator of quality of care on an SCU, must be considered in the context of a unit's case mix and the needs of its residents.

Percent of Residents Receiving One-On-One Care At Any Given Time in SCUs



APPENDIX G

**DRAFT GUIDELINES FOR
DEMENTIA SPECIFIC CARE UNITS (DSCUs)
FOR MEMORY IMPAIRED OLDER ADULTS**

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Suncoast Gerontology Center
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Forward

The Guidelines for Dementia Specific Care Units (DSCUs) for Memory Impaired Older Adults is a product of the National Resource Center on Alzheimer's Disease. The National Resource Center is housed at the University of South Florida's Suncoast Gerontology Center, and is funded by the Administration on Aging. Its mission is to build capacity among State Units on Aging for establishing effective service programs which deal with the problems of recognition, diagnosis, short term treatment and long term management of Alzheimer's Disease patients and the needs of their family caregivers. The National Resource Center staff's experience in the area of Alzheimer's Disease comes from their involvement in numerous projects of the Suncoast Gerontology Center in the last ten years.

State and Area Agencies on Aging have indicated that as special care units are developed in nursing homes and other institutional settings they receive many inquiries concerning the design, organization and components of such a unit. These Guidelines have been prepared to answer some of those questions.

This publication will be of interest to State and Area Agency staff, nursing home personnel such as administrators, directors of nursing, and activity directors, as well as personnel in existing special care units. These Guidelines are intended to assist in the organization and implementation of special care units and should not be regarded as definitive criteria for licensing or regulating such units.

Users of these guidelines are encouraged to consult the bibliography and become familiar with the literature of dementia specific care units.

I. INTRODUCTION

Memory impairment in older adults, particularly Alzheimer's Disease and related dementias, has captured the attention of researchers, policymakers and practitioners alike. In fact, few today would argue with the statement that Alzheimer's Disease is perhaps "the disease of the century."

Current estimates indicate that approximately 3.75 million Americans 65 years of age and older suffer from AD and other forms of dementia. Moreover, the number of cases of Alzheimer's is expected to increase sharply by the year 2050, with an estimated 14.3 million individuals afflicted with the disease (Evans, et. al., 1989).

While many memory impaired older adults in the early stages of the disease remain in the community under the primary care of their loved ones, as the disease increases in severity and the resiliency of the family to provide care diminishes, there is an increased probability that the afflicted person will be institutionalized in a nursing home. Indeed, of those elderly in nursing home settings, approximately 60% suffer some form of cognitive impairment (U.S. Department of Health and Human Services, NCHS, 1987) and the number and proportion will likely grow.

This increase in the demented population, coupled with the likelihood of institutionalization, has had a significant impact on the nursing home industry. Increasing numbers of nursing homes are creating Dementia Specific Care Units (DSCUs) (Coons, 1991). In fact, as the title of an article by Jaswiecki (1986) rather boldly declares: "Alzheimer's [and other forms of dementia] Can be a Catalyst for Industry-Wide Change."

The concept of special care units is a concept that the nursing home industry has been trying to put in practice for the past ten years with some guidance from the research community in the belief that segregation of Alzheimer's patients provides a better environment for residents who are not demented, and provides an opportunity to give greater attention to the needs of those who are. Because evaluation of the impact of such segregation has not been systematic, and operational cost incentives are not clear-cut, neither the pace of this change has been sufficient nor has the application of the concept been consistent. Projections for the availability of specialized units within the nursing home industry clearly indicate a shortfall. Recent data from the 1987 Institutional Population component of the National Medical Expenditure Survey (NMES) (DHHS Agency for Health Care Policy Research, 1990) indicates that there are roughly 640,000 patients with dementia or almost 12 times the current 54,000-bed patient capacity. The report quite correctly goes on to state that "not every nursing home resident with cognitive impairment associated with Alzheimer's Disease or a related dementia may need care in a specialized unit, but the potential demand clearly exceeds supply by a substantial margin."

Coupled with the insufficient scope on the supply side, there is extreme variability among those special care units which have been developed. For example, Ohta and Ohta (1988) report, on the basis of an analysis of predominantly secondary data, that there is extreme diversity across units with regard to philosophy (definition of special, primary beneficiary, focus of patient care), environmental design (staff to patient ratio, staff consistency, staff training, admission/discharge criteria). A study by Hepburn, et al. (1980) echoes the findings of Ohta and Ohta. In their study of facilities in Minnesota, it was found that the major concern of DSCUs was for the management of

disruptive patients, with an indifference to accurate diagnosis and preoccupation with behavior as an admitting criteria.

In a more recent study by Cairl, et. al., 1990, the extent of diversity in application of the concept was identified through actual site visits to a sample of 13 DSCUs in nursing homes covering a ten-county area in West Central Florida. The findings indicated that for some nursing homes, the concept translates into a formal commitment to providing a unique environment specifically designed to address the characteristic problems and needs of dementia patients and family members. For others, the concept, in practice, simply represents a method of controlling disruptive behavior, with little attention to the creation of a unique environmental design or the programming of special activities.

Finally, in perhaps one of the most comprehensive and recent studies performed by Gold, et. al. (1991) the extent of heterogeneity clearly emerged. In examining 55 special care units across five states, Gold and her associates determined that there were relatively few DSCUs which could be categorized as either exemplary or, on the other side of the coin, inferior. For the most part, the DSCUs studied fell somewhere in between exceptionally good and exceptionally bad.

The diversity found in the application of the concept of DSCUs in practice may well result from the limited theoretical knowledge currently available on appropriate models of care for memory impaired older adults as well as the limited experimental and quasi-experimental data on the potential impact of these units. Empirical research which would address the impact of DSCUs has tended to suffer from methodological problems and/or have not reflected the variability in the applications of the concept in practice (Benson, et. al., 1986; Cameron, et. al., 1987; Cleary, et. al., 1988; Greene, et. al., 1985; Hall and Buckwater, 1986; Holmes, et al., 1990; Linsk and Miller, 1986; Mathew, et. al., 1988).

Despite the lack of evidence on the efficacy of these units, the concept of specialized care continues to attract advocates both within and outside the nursing home industry. Advocates of the concept argue that the mixing of demented and non-demented patients has a demoralizing effect on all nursing home residents as well as staff. Specifically, they contend that the demented patient who typically wanders, is incontinent, and (often, as a result of confusion) is combative, invades the privacy of the non-demented, disrupts positive interaction and socialization, interrupts sleep patterns and excites a fear of physical harm. Such behavior patterns often force staff, out of frustration, to tranquilize, overmedicate, and physically restrain demented residents (Coons, 1991; Hall et. al., 1986; Hall and Buckwater, 1986; Benson, et. al., 1986; Meir and Cassel, 1986; Mace, 1986; Rabins, 1988; Peppard,

1986; Gwyther, 1986). Moreover, this situation often leads to disillusionment among staff, who are ill-prepared for the dementia patient, leading to higher rates of turnover and burnout within facilities.

Special care units indeed appear to be a predominant wave of the future in long term care. In light of recent epidemiological projections (Evans, et. al., 1989), nursing homes will continue to design and implement the concept. Moreover, it is not likely that sufficient data will soon emerge to address the viability of the assumptions cast in defense of DSCUs.

Given this rather unique condition of growth in the absence of sound empirical verification, it is important that some guidance be offered regarding the design, implementation and operation of DSCUs. In short, draft guidelines and/or standards need to be offered from which to homogenize what is now extremely heterogeneous growth in the application of the concept.

In defense of this assertion, this brief paper offers some initial draft guidelines/standards. The guidelines themselves are broken down into the following conceptual categories.

- Therapeutic Goals and Philosophy of DSCUs
- Target Population
- Admission/Discharge
- Assessment and Follow-up Procedures
- Physical Environment
- Activities
- Unit Size and Staffing
- Staff Training
- Family Involvement
- Evaluation

It is important to note that the guidelines offered are not to be viewed from a potential regulatory standpoint. The absence of complete evidence regarding the efficacy and effectiveness of DSCUs to date, would render such a regulatory interpretation inappropriate and premature. To the contrary, the proposed draft guidelines should be used to assist in the organization and implementation of existing and prospective DSCUs, not as a point of arbitration for what should be. To the extent that the growth and implementation of these units becomes more consistent then and only then will a full picture of the potential impact be realized.

II. SPECIFIC GUIDELINES

A. Therapeutic Goals and Philosophy of DSCUs

1. Generic Therapeutic Goals of DSCUs

In many respects the generic therapeutic goals of special care units for memory impaired older adults mirror those which should be established and endorsed for all patients being cared for in long-term care facilities. On a broad conceptual level, these goals have often been loosely and implicitly captured in statements such as "preservation of dignity" and "enhancing quality of life." Clearly, these statements engender an important humanistic quality, nonetheless, they suffer from limited specificity.

In translating these rather vague statements into somewhat more concrete terms, several substantively specific therapeutic goal statements or guidelines emerge. Building, in part, on the work of Calkins (1988) and Cohen and Associates (1988), these guidelines should include the following:

Dementia Specific Care Units in institutional settings should:

- **Provide a therapeutic milieu which insures the safety and security of patients.**
- **Provide an environmental and therapeutic milieu which insures the privacy of dementia patients and enhances their capacity for self control and independent decision-making.**
- **Provide an environmental milieu which enhances the existing functional capacity of dementia patients while at the same time supports functional deficits.**
- **Provide an environmental and therapeutic milieu which is responsive to the dynamics of change in dementia patients functional capacity.**
- **Provide a therapeutic milieu which minimizes the use of pharmacologic restraints and utilizes physical restraint as a last resort.**

In essence, these guidelines reflect an emphasis on providing the memory impaired older-adult with an environment which stimulates their maximum functional independence despite limitations in activity or

progressive deterioration of physical and cognitive functioning. Moreover, this environment should be safe, humane and minimally restrictive.

2. Philosophy of DSCUs

The identified therapeutic guidelines for DSCUs tend to echo a more general philosophy or conceptual orientation to care. Although there is less than complete consensus regarding this philosophy, there is, nonetheless, rather consistent endorsement of the position that an effective milieu for the care of memory impaired older adults should be sensitive to the diminished stress thresholds of these adults.

This philosophy has, over the course of the past few years, emerged out of two distinct yet complementary perspectives. Lawton (1980), offered to the geriatrics and gerontological community an Environmental Docility Hypothesis which essentially states that as cognitive competence decreases, external environmental factors become increasingly important determinants of behavior and affect. In short, there is an inverse relationship between physical and cognitive functional capacity and the relative importance of the environmental milieu as a therapeutic intervention in and of itself.

Building, in part, on Lawton's hypothesis, Hall and Buchwalter (1987) offered their Progressively Lowered Stress Threshold (PLST) model to the gerontological community. This model, which has become widely discussed and implemented, essentially draws upon the pioneering theoretical work of Lazarus (1966), on stress and coping behavior.

The PLST model essentially argues that as a result of memory loss and the progressive nature of dementing diseases, patients experience a gradual intolerance to multiple stimuli. As a function of time, this increased intolerance heightens the patients level of fatigue, anxiety, avoidance behavior and catastrophic reactions. To counteract these deficits and the corresponding behavioral manifestations, the environment should be explicitly designed and organized so as to reduce or minimize overstimulation while at the same time supporting losses and enhancing safety.

In translating these theoretical positions, the following specific guidelines regarding the philosophy of DSCUs emerge:

- **The approach to care should support all areas of loss in a prosthetic manner.**
- **Levels of stimuli and activity should be established for individual patients based upon their exhibited anxiety and avoidance behavior patterns, with sensitivity to variations in**

progressively lowered stress thresholds.

B. Target Population

The work of Ohta and Ohta (1988), Hepburn, et al. (1989), Cairl, et al. (1991), and Gold, et al. (1991), clearly indicates that behind the label of special care units, there is considerable heterogeneity in design and function. One area in which this heterogeneity is particularly pronounced is with regard to the designated target population of DSCUs. Current evidence indicates that some DSCUs are specifically designed and targeted for Alzheimer's Disease patients. Others serve a mixed population of demented patients (e.g., Alzheimer's Disease, Infarct-Dementia, Vascular Dementia). Still others serve a mixed population of individuals with dementia and individuals with non-organic based disease i.e., depression.

While the evidence, to date, regarding the appropriateness and effectiveness of mixing sub-groups of demented and/or demented and non-demented is vague and insufficient, there are nonetheless, several guidelines which can be established relative to the target population of DSCUs. These guidelines are as follows:

- **Individual DSCUs should clearly define and designate the population which it is capable of serving and restrict admission within the confines of that definition and designation.**
- **Individual DSCUs should not provide services to those patients whose needs exceed resources or for whom a more appropriate level of care is indicated.**
- **In determining the appropriateness of a patient, individual DSCUs should fully consider the range of needs of the patient, and the availability of services and activities to meet these needs.**

C. Admission/Discharge

1. Admission Criteria

The admission criteria for DSCUs should correspond to the designated target population, range of services and activities provided, and the level of functioning of the prospective patient. Translating these general principles into somewhat more concrete terms, the following guidelines should be considered:

Admission to a DSCU should, at a minimum, be restricted to:

- Patients who have, through physician diagnosis and neuropsychological testing, been identified as having a dementia
- Patients who have the strength and stamina to participate in the DSCU therapeutic program of activities and are not otherwise bedfast, experiencing long-term physical incapacity due to chronic medical condition(s), or exhibiting extremely disruptive behavior manifestations which would undermine the therapeutic milieu.

2. Discharge Criteria

Discharge from a special care unit should, at a minimum, be based upon the following criteria:

Patients should be discharged from an DSCU when:

- The patient develops a long-term chronic physical health condition in which the prognosis indicates a potential need to be bed fast or otherwise indicates a significant reduction in the patients ability to participate in the activities programming of the DSCU.
- The patient exhibits a marked decline in functional capacity which prohibits participation in the activities of the DSCU.
- The patient exhibits behavior patterns for which the staff has determined, as a function of time, to be unnecessarily obstructive to the activities program of the DSCU.

D. Assessment and Follow-up Procedures

1. Comprehensive Assessment

One of the hallmarks of contemporary geriatrics and gerontology is the investment which has been placed on comprehensive multi-dimensional assessment technology (Kane and Kane, 1988; Gallo, et al., 1988). Good care of the cognitively impaired elderly indeed requires a broad and innovative outlook. The fact that the patient is being admitted to an institutional setting should not and does not preclude the need for systematic comprehensive assessment. To the contrary, given the predominant pattern of admissions to

DSCUs of persons who are moderately to severely cognitively impaired yet otherwise only mildly to moderately physically impaired, the role of comprehensive assessment in accurate and systematic individualized care planning becomes fundamentally important.

Accepting this fact, DSCUs should invoke the following guidelines regarding patient assessment:

- **Prior to consideration for admission, DSCU staff should secure a current medical report (based upon an examination completed within the six-months prior to admission) from the patient's family and/or designated physician(s). The medical report should include any acute or chronic diagnoses, medications and medication regimen, and corresponding treatment recommendations.**
- **All prospective admissions for the DSCU should receive a preadmission comprehensive assessment completed by a trained staff person assigned to the special care unit. The assessment protocol to be administered should address, at a minimum, the following domains of functioning:**
 - **patient psycho/social history**
 - **patient family support**
 - **patient level of activities functioning**
 - **patient ADL functioning**
 - **patient level of behavioral impairment**
 - **patient medical assessment**
 - **patient level of cognitive/memory functioning**
 - **family caregiver(s) anticipations and desires for placement of the patient**
- **Each comprehensive assessment should be formally reviewed by multi-disciplinary team composed of individuals directly responsible for the provision of care to the patient within the DSCU.**
- **Based upon the team review, a formal care plan should be drafted, reviewed and discussed with the designated family caregiver(s).**

It is important to note that the care plan should include clear specification of the patients strengths, needs, and problems with

corresponding reference to an individualized set of activities designed to support existing functional deficits and maximizing existing functional capacities. The care plan should also include a realistic specification of potential objectives and outcomes stated in both long and short term form. In addition, the care plan should clearly specify any services which are needed by the patient which are beyond the existing services provided within the operation of the DSCU (e.g., physical therapy, speech therapy). In this regard, appropriate specification of who these services are to be coordinated with should be included.

2. Ongoing Follow-up

Given the dynamic and progressive nature of dementing disorders it is fundamentally important that patients who are admitted to DSCUs be systematically reassessed with subsequent appropriate modifications introduced into care plans. Although the reassessment protocol may reflect a reduced version of the initial comprehensive assessment, the information gathered should be sufficient to indicate changes which have occurred in cognitive and/or functional status and the need for alternative or modified activities.

Given the importance of systematic follow-up, DSCUs should indorse the following specific guidelines:

- **All patients admitted to DSCUs should be reassessed at a minimum of every six months post admission.**
- **The assessment protocol, once administered, should be formally reviewed by staff with appropriated modifications introduced into the patients care plan.**
- **Any significant changes identified regarding the patients level of functioning or activities should be formally reported to the patients family caregiver(s).**

E. Physical Environment

In recent years there has been an increasing number of publications which focus specific attention on the physical or structural environment of DSCUs (c.f., Calkins, 1988). One of the delimiting features of this body of

literature is that the predominantly suggested architectural designs of a DSCU assumes that a "new" or "ideal" unit would or could be built. This, of course, tends to ignore the fact that due to fiscal realities, many institutional settings are unable to create, from the ground up, free standing or attached units to their existing physical plants. This fact was made clearly evident in a recent article by Gold, et. al. (1991). Gold and her associates examined a sample of fifty-five institution based DSCUs across five states. Their findings, aside from demonstrating extreme heterogeneity across settings, demonstrated that the predominant pattern of development and implementation of DSCUs was that of modifying existing wings or corridors in the facility as opposed to development through new construction.

Bricks and mortar alone do not constitute an appropriate DSCU. In addressing the issue of the physical environment, any guidelines established must endorse the fact that that which is introduced will likely represent modifications of existing structures. In this regard, there are several common denominators which should be considered, each of which are sensitive to the decreased ability of memory impaired older adults to form the cognitive images necessary to aid in orientation and wayfinding. These common denominators, established under the rubric of guidelines, include the following:

The physical environment of a DSCU should:

- **Reflect a non-institutional "homelike" image.**
- **Establish negotiable traffic patterns which allow for both internal and external mobility.**
- **Utilize signs and symbols which assist patients in wayfinding and orientation.**
- **Utilize lighting which is indirect and diffused to reduce glare.**
- **Utilize color schemes which include warm hues and accents.**
- **Utilize floor coverings, wall coverings and window treatments which are simple, avoid the use of abstract patterns or sharp color contrasts.**
- **Utilize simple, sturdy, versatile and sound absorbant furniture.**

- **Utilize soft textures to enhance tactile stimulation.**
- **Utilize personal objects to enhance a sense of individuality and orientation.**
- **Utilize space so as to insure that dining areas, activity areas and bathrooms are clearly visible.**

F. Activities

The design and implementation of a therapeutic program in a DSCU must be sensitive to two fundamental phenomena associated with memory impaired older adults. First, the wandering, restlessness, anxiousness, suspicion and catastrophic reactions often exhibited by memory impaired patients commonly results from environmental conditions and/or therapeutic activities which are overly stimulating and confusing. Secondly, the reduced stress thresholds of patients often leads to nocturnal confusion toward the end of a day. In effect, patients tend to become sensory satiated toward late afternoon and early evening and experience what many clinicians have come to refer to as a "sundowning effect".

Given these two phenomena, it is important that the activities program design for patients be designed to minimize multistimulus situations and initiate consistent or routine sets of activities which are sufficiently stimulating to invite participation yet not overly taxing or confusing.

Accepting these two phenomena, the following guidelines should be considered when designing and implementing an activities program:

- **Activities should be specifically designed for individual patients with respect to their own level of cognition and physical functioning.**
- **Every effort should be made to enhance social interaction among patients through group activities (e.g., reality therapy, remotivation therapy, validation therapy).**
- **Specific activities should be implemented to enhance patients orientation to time and space (e.g., current events, group reading of newspapers).**
- **Specific activities should be implemented to enhance the mood of patients (e.g., music therapy, pet therapy).**

- **Efforts should be made to develop existing creative capacities in patients through individual and group activities (e.g., arts and crafts).**
- **Efforts should be made to introduce activities which insure appropriate levels of exercise and mobility for patients (e.g., calisthenics).**
- **Activities should be scheduled in short time periods with a decrease in group activities toward late afternoon and early evening.**
- **Efforts should be made to implement appropriate group oriented outdoor activities (e.g., gardening, barbecues).**

G. Unit Size and Staffing

To date, limited consensus exists regarding the optimum size of a DSCU. Recent descriptive reports indicate that unit size ranges from 10 beds to as many as 120 beds. Curiously, there seems to be somewhat of an inverse relationship between the size of units and the rated quality of existing DSCU's (Cairl, et. al., 1991). The smaller the unit, the more likely the environment, activities programming, staffing pattern and overall operational philosophy approaches an "ideal". In contrast, the larger the unit, the greater the likelihood that the operation approximates traditional nursing home care.

In the absence of consensus, the following guidelines should be considered:

- **The size of a DSCU should be determined based upon careful examination of the capability of staff to organize and manage an effective program of activities with attention to proper patient care.**
- **As a general rule, optimum size should range between 15 and 20 beds per DSCU.**
- **The staffing of a DSCU should be based on a ratio of one staff person for every four patients.**
- **The staff configuration should include a designated**

unit director, a designated activities director or coordinator and an appropriate number of certified nurse assistants and aides.

- The staff ratios should vary between day and night shifts ranging from 1:4 during day shifts and 1:8 during evening shifts.

H. Staff Training

The ultimate effectiveness of a DSCU is likely to be highly dependent upon the scope of training and experience of the staff. As such, the following specific guidelines are suggested:

- Each prospective staff member in a DSCU should receive a minimum of 10 hours didactic training. The training should focus, at a minimum, the following topics:
 - Goals and philosophy of the DSCU
 - An overview of memory impairment and the dementias.
 - Communicating with the memory impaired older adult.
 - Common behavior problems of memory impaired older adults.
 - Care and management of the memory impaired older adult.
- In-service training should be provided on a bi-monthly basis for up to two hours per training session.
- Staff administration should systematically monitor staff training needs and select in-service training topics which lead to more effective on-going care and management of patients.
- In-service training should be provided by trained experts in specific topic areas.
- Opportunities should be made available to staff to

attend formal conferences, seminars and workshops on topics related to care and management of the dementia patient.

I. Family Involvement

One important aspect of the operation of a DSCU is the continued involvement of family/friends in the on-going activities of the unit. In many respects, family members themselves, through visitation and participation, serve as a therapeutic intervention. Given this, DSCUs should endorse the following guidelines:

- **Family members should be continually communicated with regarding care plans and changes in patient cognitive and functional status.**
- **Every effort should be made to encourage family members and/or friends in the daily or weekly activities of the DSCU.**
- **Whenever possible, efforts should be made to secure family members as volunteers.**
- **Formally scheduled monthly social events should be scheduled for family and friends.**
- **Efforts should be made to establish a formal support group for family/friends with scheduled interaction with key staff to the DSCU.**

J. Evaluation

An all too often unfortunate phenomena that occurs relative to the introduction of "new" and "innovative" concepts in the long-term care system is the low priority given to on-going systematic evaluation. As a result, much of what is learned or changed, over time, regarding a new concept and its implementation, is based upon anecdotal and qualitative data. This fact is particularly true with regard to the history of the development of DSCUs.

As such, prospective DSCUs should establish the following guidelines regarding evaluation:

- **Formal procedures should be established at the beginning of operation of a DSCU for recording the initial and on-going functional status of patients.**
- **Formal procedures should be established for reviewing or monitoring individual and group patient functional status patterns.**
- **A reasonable set of outcome measures should be established for a DSCU with systematic recording of data which effectively addresses the established outcome measures (e.g., use of physical and/or pharmacologic restraints; changes in behavior patterns; staff turnover).**
- **All observations and findings derived from on-going evaluation should be recorded and discussed by administration and staff. These discussions should focus on specific patient behavior patterns which need to be dealt with, alternative activities, and staff problems.**

III. SUMMARY

The draft guidelines established in the present paper were spawned out of two distinct observations. First, with the increased public attention placed on Alzheimer's disease and related disorders, there has been a corresponding concerted investment on behalf of the nursing home industry to develop and implement what is argued to be an appropriate and "special" configuration of care for dementia patients — DSCUs. Secondly, the growth and substance of these units throughout the country has been extremely heterogeneous. There are units which have been designed with special attention to modifications in the physical and therapeutic milieu appropriate to the needs of the demented patient. In contrast, there are units which barely reflect any modification from the traditional custodial model of nursing home care with the sign "DSCU" simply representing a synonym for behavior management.

In casting the guidelines, no implicit or explicit assumptions were made regarding potential translation into a regulatory form. To the contrary, the

guidelines presented simply represent an attempt to provide some assistance in the prospective growth of the concept as it is applied in practice.

It is indeed true, that given the estimates and projection for demand for specialized care for memory impaired older adults, the concept of DSCUs will continue to garner serious attention. With the growth of these units there should be a corresponding and equivalent effort to monitor and formally evaluate effectiveness and cost efficiency. This latter effort, given the nature of the concept and the absence of consensually agreed upon "best practice models", will likely demand innovative methodologies which deviate considerably from traditional standards of experimental and quasi-experimental research.

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APPENDIX H

CHECKLIST

Family Guide For Alzheimer's Care in Residential Settings

yes no

I. PHILOSOPHY — What is "special" about

Alzheimer care?

- ☐ ☐ 1. Does the Alzheimer care *mission statement* indicate benefits for you and your family member?
- ☐ ☐ 2. Are religious, cultural and unique advantages apparent for your family member?
- ☐ ☐ 3. Does the *separated dementia unit* or Alzheimer care program offer special advantages for your family member?
- ☐ ☐ 4. Does the facility have licenses you consider necessary? (State *licensure*? *Medicare certification*? *Medicaid certification*? Private *accreditations*?)

II. PRE-ADMISSION — Selecting a facility

- ☐ ☐ 5. Is a specialized Alzheimer/dementia care program available?
- ☐ ☐ 6. Is the facility location convenient for you?
- ☐ ☐ 7. Do you consider that the Alzheimer care program admission requirements are acceptable?
- ☐ ☐ 8. Do other residents have *functional capabilities* similar to those of your family member?
- ☐ ☐ 9. Is assessment done by staff to determine individual special (Alzheimer/dementia) care needs?
- ☐ ☐ 10. Is the program limited by discharge and/or transfer criteria?
- ☐ ☐ 11. Do you sense a caregiving partnership with facility staff?
- ☐ ☐ 12. Are *resident rights* addressed?
- ☐ ☐ 13. Is medical care and supervision sufficient?
- ☐ ☐ 14. Are behaviors accommodated without use of *restraints*?
- ☐ ☐ 15. Are fees and charges justified and competitive within your community?
- ☐ ☐ 16. Is Medicaid or other reimbursement available?

yes no

III. ADMISSION — Entering the facility

- ☐ ☐ 17. Do you feel support for your needs and concerns?
- ☐ ☐ 18. Are residents assisted by staff, volunteers and family?
- ☐ ☐ 19. Are *advance directives* (durable powers of attorney for health care and other determined instructions) discussed, documented and honored?
- ☐ ☐ 20. Is *autopsy* (for confirmation of diagnosis) discussed and family wishes honored?

IV. CARE PLANNING AND IMPLEMENTATION — Daily living

- ☐ ☐ 21. Will you share in developing and reviewing an individualized *care plan*?
- ☐ ☐ 22. Is care planning done by an interdisciplinary care planning team?
- ☐ ☐ 23. Are care planning meetings held regularly and/or when needed to positively address care issues?
- ☐ ☐ 24. Is there a full daily schedule of *therapeutic activities*?
- ☐ ☐ 25. Are nutrition and eating needs of residents accommodated?

V. CHANGE IN CONDITION ISSUES — Disease progression and other illness

- ☐ ☐ 26. Will diminished abilities result in transfer or discharge from the program?
- ☐ ☐ 27. Is *late stage* care and illness addressed?

VI. STAFFING PATTERNS AND TRAINING — Staff assignment and Alzheimer knowledge

- ☐ ☐ 28. Do you feel confident and comfortable with staff leadership?
- ☐ ☐ 29. Is Alzheimer/dementia specific training available for all staff?
- ☐ ☐ 30. Does the number of staff appear adequate?
- ☐ ☐ 31. Are staff pleasant and encouraging to residents?
- ☐ ☐ 32. Is there competent monitoring of medical care?

**yes no VII. THE PHYSICAL ENVIRONMENT — A place for
Alzheimer care**

- ☐ ☐ 33. Is the environment safe and comfortable?
- ☐ ☐ 34. Does the size of the program offer benefits?
- ☐ ☐ 35. Is outdoor space available and used?
- ☐ ☐ 36. Is private space personalized and respected?
- ☐ ☐ 37. Is the environment calm and pleasurable?
- ☐ ☐ 38. Do safety measures meet the needs of your family member?

**VIII. SUCCESS INDICATORS — Benefits of
Alzheimer care**

- ☐ ☐ 39. Do residents appear relaxed and content?
- ☐ ☐ 40. Are residents active and engaged in activities?
- ☐ ☐ 41. Is the atmosphere cheerful and homey?
- ☐ ☐ 42. Are residents clean and well groomed?
- ☐ ☐ 43. Do residents appear alert?
- ☐ ☐ 44. Are residents treated with dignity and respect?
- ☐ ☐ 45. Is restraint use absent or appropriate and closely monitored?
- ☐ ☐ 46. Are privacy needs and confidentiality respected?
- ☐ ☐ 47. Is there open communication among residents, families and
staff?
- ☐ ☐ 48. Are research opportunities explained?
- ☐ ☐ 49. Is the Alzheimer care program objectively evaluated?
- ☐ ☐ 50. Are all aspects of care supervised and evaluated?

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